PROFILE OF AND CHALLENGES EXPERIENCED BY STROKE PATIENTS ADMITTED TO RUHENGERI HOSPITAL IN RWANDA

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KEYWORDS

Stroke

Profile

Physiotherapy

Challenges experienced

Activity limitation

Participation restriction

Environmental barrier

Ruhengeri Hospital

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Rwanda

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ABSTRACT

Stroke is the world's third highest cause of death and a major cause of disability. In order to define optimal management for stroke, reliable data are needed. Although Ruhengeri Hospital in Rwanda receives many stroke patients, no in-depth study has been carried out on stroke patients admitted at the hospital. This study, therefore, identified the profile of stroke patients admitted at Ruhengeri Hospital in Rwanda and explored the challenges that they experienced. A concurrent mixed model design was used to collect data. With a data gathering instrument which was developed by the researcher, a quantitative retrospective approach was used to review existing patients' records to collect information related to demographic characteristics, documented clinical features and risk factors for stroke, stroke onset-admission interval, length of hospital stay and the process of physiotherapy for stroke patients. In-depth face-to-face interviews were also used to collect data regarding the challenges experienced by stroke patients. The sample for the quantitative phase consisted of medical records of stroke patients admitted at Ruhengeri Hospital from January 1st, 2005 up to December 31st, 2008. In the qualitative phase, a purposive sample of 10 participants was selected. The SPSS (16.0 version) and the Microsoft Excel Package 2007 were used to analyze the quantitative data. Descriptive statistics using frequencies, percentages, ranges, means, and standard deviations and inferential statistics using chi-square and correlation tests were calculated. For qualitative findings, audiotaped interviews were transcribed and translated from Kinyarwanda into English, and the expressed ideas were coded and reduced into themes and categories.

Permission to conduct this study was obtained from the Senate Research Grants and Study Leave Committee at the University of the Western Cape, and the concerned authorities in Rwanda. Written informed consent was obtained from the interview participants. There were 204 stroke patients, but only 139 among them were included in the analysis of the quantitative findings. The mean age of the study population was 56.3 years, and 53.2% were females compared to 46.8% of males. The majority of the participants (62.6%) were cultivators before the stroke. The most prevalent documented clinical features were emotional, cognitive, vision and speech impairments, while the most reported risk factors for stroke were hypertension, smoking and diabetes. It was found that the mean stroke onset-admission interval was seven days, while the mean length of hospital stay was 8.2 days. Out of the 139 participants, only 55 (39.6%) received physiotherapy during their hospital stay. During the in-depth interviews, participants reported activity limitations including difficulties in walking, bathing, eating, going to toilet, dressing, cooking, washing and cleaning. The participants also experienced the participation restrictions which included inability to return to work, decreased social interactions and inability to participate in religious activities. The participants also expressed the environmental barriers which included lack of social support, inaccessible physiotherapy services, negative attitudes and inaccessible pathways and toilets. The current study findings suggest appropriate and specific programmes aiming preventing stroke and addressing the activity limitations, participation restrictions and environmental barriers experienced by patients with stroke.

DECLARATION

I hereby declare that **"Profile of and challenges experienced by stroke patients admitted to Ruhengeri Hospital in Rwanda"** is my own work, that it has not been submitted for any degree or examination in any other university, and that all the sources used or quoted have been indicated and acknowledged by complete references.

Gerard Urimubenshi

Signature……………………...   **November 2009**

Witness: ………………………

      Mrs. Anthea Rhoda

DEDICATION

I dedicate this mini-thesis to my wife Marie M. GIRAMAHORO for her love, patience and support, and to my daughter Délice A. KIREZI. May God continue to protect you.

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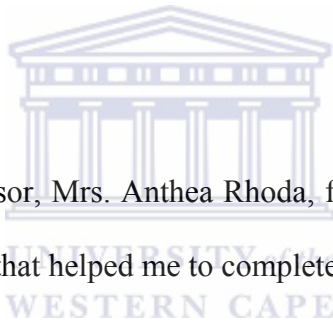
I am grateful to the participants who accepted to participate in this study.

I extend special thanks to all who assisted me in one way or the other.

I am indeed indebted to my wife Marie M. GIRAMAHORO, and our daughter Délice A. KIREZI, who provided considerable support and understanding when this thesis kept me away from them.

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ABBREVIATIONS

ADL	Activity of Daily Living
AIDS	Acquired Immunodeficiency Syndrome
ARIC	Atherosclerosis Risk in Communities
HIV	Human Immunodeficiency Virus
ICF	International Classification of Functioning, Disability and Health
LOS	Length of hospital stay
MONICA	Monitoring of Trends and Determinants of Cardiovascular Disease
MRR	Medical Records Review
PWD	People with disabilities
SASPI	Southern Africa Stroke Prevention Initiative
SD	Standard Deviation
SPSS	Statistical Package for Social Sciences
SSA	Sub-Saharan Africa
TIA	Transient Ischemic Attack
UK	United Kingdom
UN	United Nations
US	United States
WHO	World Health Organization
%	Percentage

CHAPTER ONE: INTRODUCTION

1.0 INTRODUCTION

This chapter begins with a background to the study. It presents the worldwide burden of stroke and pays particular focus on developing countries. In addition, the chapter highlights the rationale of the study. Furthermore, it presents the statement of the problem, research questions, aim and objectives of the study. It provides the definitions of key terms used in the study, and ends with an outline of the chapters of the study.
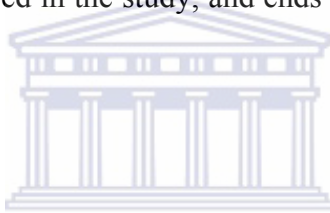
1.1 BACKGROUND TO THE STUDY

Strong evidence supports an emerging epidemic of chronic non-communicable diseases including stroke (Kengne & Anderson, 2006). Overall, stroke is the third highest cause of death throughout the world (Bakas, Austin, Okonkwo, Lewis, & Chandwick, 2002). Worldwide stroke caused an estimated 5.7 million deaths in 2005, and if this rate continues unfettered, that number will rise to 6.5 million in 2015 and 7.8 million in 2030 (Strong, Mathers, Epping-Jordan, & Beaglehole, 2006). In developed countries, stroke is the third leading cause of death, behind heart disease and cancer (O'Dell, Lin, & Harrison, 2009). This also appears to be the case in developing countries, as Murry and Lopez (1997) reported that stroke was the second

most common cause of death in 1990. In African countries, stroke represents up to 5% to 10% of the causes of death (Garbusinski et al., 2005).

According to Donnan, Fisher, Macleod and Davis (2008), two-thirds of stroke deaths worldwide occur in developing countries. In 2001, stroke killed 5.4 million in both groups of countries, of whom 85.5% were in developing countries (Matters, Lopez, & Murray, 2006).

As for stroke mortality, stroke incidence is higher in developing than in developed countries. A recent international systematic review of population-based studies on stroke, has showed that, over the four decades, age-adjusted stroke incidence rates in developed countries decreased by 42% (from 163 per 100 000 people in 1970–1979 to 94 per 100 000 people in 2000–2008; p=0.0004), whereas in developing countries the stroke incidence rates more than doubled (52 per 100 000 and 117 per 100 000 people, respectively; p<0.0001) and exceeded the rate observed in developed countries in the last decade (Feigin, Lawes, Bennett, Barker-Collo, & Parag, 2009). The increase in stroke incidence observed in developing countries is due to both the populations' rapid ageing as well as social and environmental changes that are leading to an increase in the prevalence of common, preventable risk factors in those developing countries (WHO, 2005).

Contrary to mortality and incidence, the literature suggests that the stroke prevalence is higher in developed than in developing countries. In these countries, it has been found that the prevalence of stroke is 500 to 800 per 100,000 people (Fieschi, Falcou,

Sacchetti, & Toni, 1998). A systematic literature review conducted by Kengne and Anderson (2006) on the burden of stroke in Sub-Saharan Africa (SSA) recorded much lower rates between 200 and 300 per 100,000.

The impact of stroke is vast. Stroke is a major cause of long-term disability (Bakas et al., 2002), and has potentially enormous emotional and socioeconomic results for patients, their families, and health services. According to Warlow, Dennis, van Gijn, Hankey and Sandercock (2001), the outcome of stroke is as follows: one year after a stroke, about 30% of patients will be dead, and of the survivors, almost 40% will be dependent on others for their daily activities. Although some patients continue to show improvement up to one year after stroke, this does not reach statistical significance for the group as a whole, and between 3 and 5 years many patients experience increasing disability rather than improvement, perhaps due to comorbidity and increasing age (Kaplan, 2005). A study conducted in developed countries by Caro, Huybrechts and Duchesne (2000), showed that the lifetime costs per patient are estimated at between US Dollars 59 800 and US Dollars 230 000. In developing countries, the cost of care for stroke has been estimated at US Dollars 157 per episode, which is high in those countries where most of the population lives below the poverty line (Kengne & Anderson, 2006). The increase in stroke incidence in developing countries will have severe effect on the health care systems, resources, and economies in these countries, while they are still struggling to manage the impact of infectious diseases (WHO, 2005). Therefore, further studies are needed to define

optimal management and limit short-term and long-term morbidity and mortality of stroke (Garbusinski et al., 2005).

Compiling a profile of stroke patients would give data that could be used to develop appropriate prevention and rehabilitation strategies for patients with stroke (Feigin, Lawes, Bennett, & Anderson, 2003; Kengne & Anderson, 2006). Profile is defined as a brief description that summarizes the characteristics of somebody or something (Encarta Dictionary, 2007). Profile of stroke would include the demographic characteristics of the people affected (Rathore, Hinn, Cooper, Tyroler, & Rosamond, 2002), its causes and types (Lawrence et al., 2001), risk factors (Garbusinski et al., 2005), clinical features (Lawrence et al., 2001) and its rehabilitation (Yavuzer, Küçükdeveci, Arasil, & Elhan, 2001).
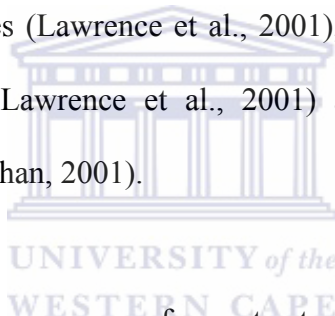
In developed countries, the mean age for acute stroke is 75 years (Graham, Kruger, Teasell, Foley, & Salter, 2008). However, stroke affects younger people in developing compared to developed countries, and in Africa, possibly 10 to 15 years earlier than in developed countries (Walker et al., 2000). Stroke in younger people results in a greater number of years of potential life lost (Lemogoum & Bovet, 2005). With regard to gender, males in general have slightly higher age-adjusted stroke rates than females. It has been found that one in 10 men compared to one in 15 women are at risk of suffering a stroke between the ages of 45 and 75 years (American Heart Association, 2001).

Many studies have reported that the occurrence of stroke is associated with some modifiable risk factors led by hypertension (American Heart Association, 2008). It has been suggested that the reduction of stroke mortality and disability is likely to come from appropriate prevention and control of its risk factors (Strong, Mathers, & Bonita, 2007). Therefore, a comprehensive picture of the most common risk factors for stroke could assist in designing appropriate prevention strategies and thus limit the stroke burden in the increasingly elderly population (Leoo, Lindgren, Petersson, & von Arbin, 2008).

A large body of literature indicates that stroke results in a multitude of clinical features which can include: motor and sensory impairments, cognitive and perceptual impairments, communication and swallowing difficulties, urinary dysfunction, and emotional alterations (Barker, Reid, & Cott, 2006). The knowledge of the most frequent impairments occurring in a population following stroke, could assist in planning the resources needed to target and address those impairments.

Whether a patient who has had an acute stroke dies, survives in a disabled state, or recovers completely is determined by many factors. One of these factors is the process of stroke care (Weir, Sandercock, Lewis, Signorini, & Warlow, 2001). Stroke survivors present a range of disabilities which have been shown to benefit from rehabilitation, in particular physiotherapy, and patients themselves tend to have high expectations of the extent of recovery they can achieve through physiotherapy (Wiles, Ashburn, Payne, & Murphy, 2004).

The information on the process of physiotherapy for stroke can therefore direct the development of new physiotherapy services to be effective and appropriate.

In addition to the above-presented profile of stroke patients, it is also highlighted that the experiences of living with stroke are critical (Salter, Hellings, Foley, & Teasell, 2008). According to Ch'Ng, French and Mclean (2008), understanding the challenges faced by those who have suffered a stroke is useful to identify the longer-term issues that primary care based services for stroke will need to address. Suffering a stroke challenges the assumptive identity, self-concept and role-capacity of the individual in the face of acquired deficits (Salter et al., 2008). Stroke patients also experience environmental barriers which are often construed as physical but also include prejudice, stereotypes, inflexible organizational procedures and practices, inaccessible information, buildings and transport (Swann, 2008).

Although data about stroke is available in developed and in some developing countries (Feigin, 2007), no available study has been conducted on stroke in Rwanda to date. The only statistics by extrapolation estimate the prevalence and incidence of stroke in Rwanda to 1.7% and 0.22% respectively (US Census Bureau, 2004). These statistics used for prevalence and incidence of stroke were typically based on US, UK, Canadian and Australian statistics, and were automated and did not take into account any cultural, environmental, socio-economic or other differences specific to Rwanda (US Census Bureau, 2004).

According to the experience of the researcher, Ruhengeri Hospital in Rwanda receives many stroke patients, and this indicates a significant incidence of stroke in Musanze District served by the Ruhengeri Hospital. While the evidence accumulated shows that effective stroke rehabilitation requires a multidisciplinary team and equipped stroke units (Pollack & Disler, 2002), stroke patients at Ruhengeri Hospital are admitted and managed in general medical wards of the internal medicine or intensive care unit departments. Furthermore, the stroke care consists of medical and physiotherapy management only. After observing that the stroke patients are discharged very early and that there is no follow-up rehabilitation post-discharge, the researcher believes that the discharged patients experience many problems. In the absence of data on the potential burden of stroke, though, it is difficult to develop appropriate strategies to prevent stroke and its impact (Kengne, Amoah, & Mbanya, 2005). Strong et al. (2006) highlight that misunderstandings of chronic diseases such as stroke have contributed to their global neglect.

1.2 STATEMENT OF THE PROBLEM

To the researcher's knowledge, no study has been carried out on the profile of stroke patients seen at Ruhengeri Hospital in Rwanda as well as the challenges they experience. The lack of information on the stroke patients' profile and experiences would be a barrier for planning the appropriate services for them. This would inevitably lead to an increase in suffering, poor coordination and inefficient use of health services, and place the population at the mercy of treatment and prevention

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strategies with primarily local and/or global commercial interests and with poor outcomes for the patients (Unwin et al., 2001). The researcher therefore decided to identify the profile of stroke patients admitted at Ruhengeri Hospital and their challenges experienced.

1.3 RESEARCH QUESTIONS

The specific research questions addressed in this study are:

1. What is the profile of stroke patients admitted at Ruhengeri Hospital in Rwanda?
2. What are the challenges experienced by stroke patients admitted at Ruhengeri Hospital in Rwanda?

1.4 AIM OF THE STUDY

The overall aim of this study was to identify the profile of and challenges experienced by stroke patients admitted at Ruhengeri Hospital in Rwanda from January 1st, 2005 up to December 31st, 2008.

1.5 OBJECTIVES OF THE STUDY

In order to achieve the aim of this study, the following objectives were identified:

1. To determine the demographic characteristics of stroke patients admitted at Ruhengeri Hospital: age, gender, marital status and occupation before stroke

2. To determine the medical characteristics of stroke patients admitted at Ruhengeri Hospital

    2.1 To determine the clinical features of stroke among the patients

    2.2 To determine the risk factors for stroke among the patients

3. To identify the stroke onset-admission interval and the length of hospital stay

4. To identify the process of physiotherapy for the stroke patients

    4.1 Percentage of stroke patients who received physiotherapy

    4.2 Time of commencement of physiotherapy since admission

    4.3 Duration of physiotherapy

    4.4 Total number of physiotherapy sessions received by each patient

5. To explore the challenges experienced by stroke patients admitted at Ruhengeri Hospital
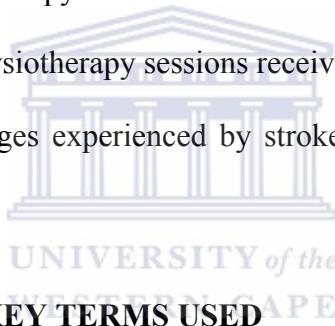
1.6 DEFINITIONS OF KEY TERMS USED

Activity: the execution of a task or action by an individual (WHO, 2001).

Activity limitations: difficulties an individual might have in executing activities (WHO, 2001).

Challenge: something needing great mental or physical effort in order to be done successfully and which therefore tests a person's ability (Cambridge Advanced Learner's Dictionary, 2008).

Disability: an umbrella term for impairment, activity limitation and participation restriction (WHO, 2001). It denotes the negative aspects of interaction between an individual who has a health condition and the individual's contextual factors which are environmental and personal factors (WHO, 2001).

Environmental barriers: environmental barriers refer to environmental factors that impede the performance of participation in life activities (Doyle & O'Donovan, 2008).

Environmental factors: constituents of the person's life milieu that can influence the accomplishment of daily activities or social roles (Rochette, Desrosiers, & Noreau, 2001).

Impairment: problem in body function or structure as a significant deviation or loss (WHO, 2001).

Participation: involvement in a life situation (WHO, 2001).

Participation restrictions: problems an individual may experience in life situations (WHO, 2001).

Stroke: stroke, also referred to as a cerebrovascular accident "CVA", is defined by the World Health Organization (WHO) as "rapidly developing signs of focal or global disturbance of cerebral or intracranial neuronal function with symptoms lasting for more than 24 hours or leading to the death of the patient with no apparent cause other than that of vascular origin (WHO Monica Project, 1988)". This definition excludes transient ischemic attacks (TIA) (which last for less than 24 hours), subdural or extradural hemorrhage, and infarction or hemorrhage secondary to infection or malignancy (Bonita, 1992).

1.7 OUTLINE OF THE CHAPTERS OF THE STUDY

Chapter one describes the basis of the current study. This begins with a description of the background of the current study, in which the stroke burden in both developed and developing countries is highlighted. It is followed by the problem statement, research questions, aim and objectives of the study. The chapter ends with the definitions of terms used in the study.

Chapter two of the thesis presents the literature review, which includes the types and causes of stroke, as well as the epidemiology of stroke including its incidence, mortality and prevalence. It continues with the risk factors for stroke, the clinical features of stroke and the rehabilitation of stroke patients. Finally, the challenges experienced by stroke patients are reviewed.
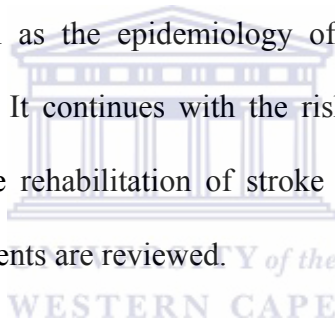
Chapter three describes the methodology used in the current study. The study setting for the quantitative and qualitative phases of study, study design, study population and sample for both phases are also described. Furthermore, other methodological issues including the study instrument for the quantitative phase of the study, the procedure of both quantitative and qualitative data collection and analysis are described. Finally, the ethical considerations adhered to during the execution of the study are explained.

Chapter four presents the results of the quantitative phase of the study. Ranges, means, standard deviations, frequencies and percentages are used to present descriptive statistics while the chi-square and correlation tests are used to test associations between certain variables.

Chapter five discusses the quantitative results relative to available literature, and the implications of the findings are discussed.

Chapter six presents and discusses the qualitative results. In this chapter, the categories and themes that emerged are presented. The discussion centers on an attempt to interpret the current study findings, and a comparison of the study results is made with similar studies. The ways the existing challenges experienced by the participants could be reversed are also discussed.

The final chapter entitled 'Summary, limitations, conclusion, significance of the study and recommendations', draws pertinent inferences from the research and proposes suggestions for future action.

CHAPTER TWO: LITERATURE REVIEW

2.0 INTRODUCTION

The body of literature relating to stroke is vast, covering topics which range from the aetiology, epidemiology and rehabilitation to relevant aspects relating to stroke consequences. This chapter of literature review will cover the existing knowledge relevant to the present study. The chapter is organized into six major sections. The first section focuses on the review of the literature relating to the types and causes of stroke. The second section reviews the epidemiology of stroke comprising the incidence, mortality and prevalence of stroke. The third section concerns the risk factors for stroke, and the fourth section reviews the stroke clinical features. The fifth section focuses on rehabilitation of stroke patients. Finally, the challenges experienced by stroke patients as reported in the literature are discussed.

2.1 TYPES AND CAUSES OF STROKE

A stroke can be classified into two main types which are ischemic stroke and hemorrhagic stroke (WHO, 1989). These classifications are based on the underlying cause. An ischaemic stroke occurs as a result of an embolus or thrombus blocking a cerebral artery while a hemorrhagic stroke occurs as a result of a ruptured cerebral artery (Hicks, 2007).

The majority of strokes occur as a result of a cerebral infarction (Thrift, Dewey, Macdonell, McNeil, & Donnan, 2001). A retrospective analysis of 228 patients with stroke admitted at the University Hospital of São Paulo in Brazil from 1989 to 1993, revealed the following distribution of stroke types: 53% of patients had ischemic strokes, 26% had hemorrhagic strokes, 2% had association from both and 19% were not specified (Radanovic, 2000). Data from a hospital-based stroke register in Cape Town, of 1000 patients with first ever stroke, captured between 2000 and 2006 also revealed that ischemic infarction resulted in 81% of all stroke in patients older than 45 years, while primary cerebral hemorrhage accounted for 11% of strokes leaving 8% unidentified causes (Bryer, Tipping, & De Villiers, 2006).

An accurate diagnosis of the type of stroke can only be done conclusively following a Computerized Tomography (CT) scan or Magnetic Resonance Imaging (MRI) (Connor, 2006). As CT scan investigations are however expensive and therefore not freely available in developing countries and more so in rural areas (Kengne & Anderson, 2006), Pougvarin (1998) suggested the use of the Sirija stroke score to clinically distinguish between the two types. The Sirija stroke score is the method most likely used for the identification of the stroke types in Rwanda, as there is only one referral hospital in Rwanda which has CT scan equipments.

2.2 EPIDEMIOLOGY OF STROKE

The epidemiology of stroke can be described in terms of incidence, mortality and prevalence (Warlow, 1998).

2.2.1 Incidence of stroke

The incidence of a disease is the number of new cases presented over a given period (Terent, 2003). The documented incidence of stroke varies according to age, gender, race and geographical location (Stansbury, Jia, Williams, Vogel, & Duncan, 2005).

The age-specific incidence of stroke increases progressively with each decade of life (American Heart Association, 2001; Feigin et al., 2003). A systematic review conducted by Feigin et al. (2003) to analyze published population-based studies on stroke included 15 studies and showed that the incidence rate of stroke for those aged less than 45 years ranged from 0.1 to 0.3 per 1000 persons; but for those aged 75–84 years, the range was 12.0–20.0 per 1000 persons in most studies. This is also illustrated by the study findings showing that stroke occurs mostly in old people. For all individuals who experience stroke worldwide, only 20% are under the age of 65 and only 5% of all stroke patients have been found to be younger than 45 years (Johansson, Norrving, & Lindgren, 2000).
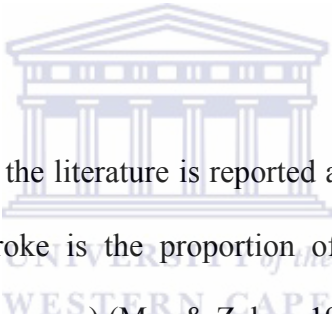
In general, the incidence of stroke is higher in males than in females (American Heart Association, 2001). According to Wolfe (2000), men have a 25-30% increased chance of having a stroke compared to women. However, it has been found that the stroke incidence with regard to gender versus age group is as follows: men's stroke incidence rates are greater than women's at younger ages but not at older ages. The male: female incidence ratio is 1.25 at ages 55–64; 1.50 for ages 65–74; 1.07 at 75–84 and 0.76 at 85 and older (American Heart Association, 2009). The higher incidence of stroke in women at older age could be attributed to the fact that the life expectancy of women is longer than males: it was found that women live on average 3.9 years longer than men (Mathers, Sadana, Salomon, Murray, & Lopez, 2001).

The incidence rate also appears to be higher in blacks than in whites. Stanbury et al. (2005) also conducted a literature review of ethnic variations in stroke epidemiology. They found the incidence rate of stroke to be 288/100 000 among the blacks compared with the rate of 179/100 000 for the whites in Minnesota (US). This racial disparity may be due to the socioeconomic conditions of those racial groups.

The incidence of stroke also varies in different parts of the world. For example, a prospective comparison of stroke data across countries showed that out of 2074 strokes registered over the 3 years, the incidence rate to the European population was 100.4 per 100 000 in Dijon (France), 123.9 in London (UK) , and 136.4 in Erlangen (German) (Wolfe et al., 2000). This study used population-based stroke registers of between 1995 and 1997 for all age groups in Erlangen, Dijon, and London.

Literature also indicates variations of stroke incidence within the same country. For instance, a medical records review conducted by Engström et al. (2001) at Malmö University Hospital in Sweden revealed that the incidence rates (per 100 000) ranged among different residential areas from 437 to 743 among men and from 223 to 518 among women. Despite the burden of stroke in developing countries, no population-based stroke incidence studies have been conducted in Sub-Saharan Africa (Kengne & Anderson, 2006).

2.2.2 Mortality of stroke

The mortality of stroke in the literature is reported as mortality rate and case fatality rate. Mortality rate of stroke is the proportion of deaths caused by stroke in a specified period (usually one year) (Mas & Zuber, 1993). Stroke, which causes 10% - 12% of all deaths, is the third leading cause of death, following heart disease and cancer in industrialized countries (Bonita & Beaglehole, 1993). In developing countries also, stroke was reported to be the second most common cause of death in 1990 (Murray & Lopez, 1997). Case fatality rate for stroke is the proportion of patients with stroke who die within a specified period after the stroke onset (usually 30 days) (Bonita, 1992). The documented case fatality rate for stroke varies with location, age, type of stroke, the number of stroke events and the stroke risk factors.

A systematic review, including 13 published population-based studies on stroke, conducted by Feigin et al. (2003) revealed that the case-fatality of total strokes within one month of stroke onset varied little between countries, with the exception of Japan (17%) and Belluno, Italy (33%). This variation might be little; however, as reported by Feigin et al. (2003) because most of the studies reviewed were from developed countries. Other studies indicate that case fatality rates are higher in poorer developing countries than in the more affluent developed countries. For example, in Gambia it was found to be 46% (Garbusinski et al., 2005) while in Scotland, the overall 30-day case mortality rate for stroke is approximately 20% of the stroke patients (Scottish Intercollegiate Guidelines Network, 2002). The higher case fatality rates for stroke in developing countries can be related to limited healthcare facilities and uncontrolled risk factors such as hypertension (Walker et al., 2000).

Older people are significantly more likely to die after a stroke (Connor, Thorogood, Casserly, Dobson, & Warlow, 2004); case fatality rate is twice as high in patients aged over 85 years as those below 65 years (Bamford, Sandercock, Dennis, Burn, & Warlow, 1990).

Although the ischemic stroke accounts for 70% to 80% of all strokes, it was found that the case fatality is higher in hemorrhagic than in ischemic strokes. After 9-year follow-up of stroke cases, Rosamond et al. (1999) found that the 30-day case fatality rate for ischemic strokes was 7.6% compared to 37.5% of hemorrhagic strokes. Similar results were also found in a review of medical records of stroke patients

hospitalized at New York University Downtown Hospital in New York City from January 1995 to July1998 (Fang, Foo, Jeng, Yip, & Alderman, 2004). The authors reported that 13.2% of the patients died at hospital, and stratifying by type of stroke, in-hospital death was significantly higher among hemorrhagic than ischemic stroke patients (34.5% versus 6.1%, respectively, *P*<.001).

Another factor associated with case fatality rate for stroke is the number of stroke events. The literature indicates that patients with recurrent strokes have lower short and long-term survival compared to patients with first-ever strokes, regardless of age. For instance, in a review of the files of the patients admitted with stroke in US due to cerebral infarction and aged 65 years and older, it was found that survival from first stroke is consistently better than that for recurrent stroke: 24-month survival was 56.7% versus 48.3%, respectively (Samsa, Bian, Lipscomb, & Matchar, 1999). However, these findings cannot be generalized as the sample was limited to an age group of 65 years and above, as well as to stroke only due to cerebral infarction. In addition to the mentioned factors, the stroke case fatality was found to be associated with hypertension, blood glucose level, history of coronary heart disease, and diabetes (Fang et al., 2004), but this has still to be clarified.

2.2.3 Prevalence of stroke

The prevalence of a disease refers to a proportion of the population affected by a specific disease at a given time (point prevalence), or at a certain period (Orencia & Ballard, 1993). Prevalence of stroke means the estimated population of people with stroke at any given time (US Census Bureau, 2004). The average age-adjusted prevalence of stroke is reported to be 501 per 100 000 of the world population (Terent, 1993).

Literature indicates that stroke prevalence increases with age. A European study showed that the prevalence of stroke increased from 5% in people aged 65 years, to 7% in those aged 75 years (Di Carlo et al., 2000). Stroke prevalence also varies with gender. A systematic review of 15 population-based studies conducted by Feigin et al. (2003) revealed that the age-standardized prevalence for people aged 65 years or more ranged from 32.2 to 61.2 per 1000 population for women, but ranged from 58.8 to 92.6 per 1000 population for men. In South Africa, however, the SASPI Project Team (2004) conducted the first prevalence study and recorded a higher prevalence rate for females (348 per 100,000) than for males (246 per 100,000). The information gained from the studies conducted in various countries shows the extent of the stroke in different populations. However, such information is lacking for many developing countries (Kengne & Anderson, 2006) including Rwanda.

2.3 RISK FACTORS FOR STROKE

The risk factors for stroke have been divided into non-modifiable and modifiable risk factors (Salter, Teasall, Foley, Bhogal, & Speechley, 2007).

2.3.1 Non-modifiable risk factors

Age, gender, race, previous stroke and previous Transient Ischemic Attack (TIA) are regarded as the non-modifiable risk factors for stroke. Information concerning the effects of age, gender, race as they relate to stroke has already been mentioned in the section on the epidemiology of stroke. With regards to previous stroke, it was found to be a significant risk factor for recurrent stroke and more so during the first year post-stroke. The results of the Oxford Community Stroke Project revealed that the risk for stroke was 15 times greater for stroke survivors than for the population in general (Burn, Dennis, Sandercock, Wade, & Warlow, 2005). History of a TIA has also been found to be a significant predictor of stroke (Hankey, 2003). Five to 10 percent of patients presenting with TIA will have a stroke within the following week (Ebell, 2006).

2.3.2 Modifiable risk factors

Modifiable risk factors for stroke include: hypertension, diabetes, elevated blood lipid levels, physical inactivity, smoking, alcohol abuse and cardiac diseases (Salter et al., 2007). These factors result from the individual's lifestyle and could therefore be

prevented. The following well-established modifiable risk factors for stroke will be discussed: hypertension, diabetes, smoking, alcohol abuse and cardiac diseases.

Hypertension is widely considered as the major contributor to stroke in the general population (Tegos, Kalodiki, Daskalopoulou, & Nicolaides, 2000; Salter et al., 2007). Strong evidence exists indicating that the control of hypertension is associated with a reduced risk of stroke, particularly in patients with a history of intracerebral haemorrhage (Salter et al., 2007). The risk of stroke is said to increase proportionately with the increase in systolic and diastolic blood pressure. In individuals with a systolic pressure of ≥140mmHg and diastolic pressure of ≥ 90mmHg the lifetime risk of stroke is significantly increased when compared with individuals with normal blood pressure (Seshadri et al., 2006).

Diabetes is another well-established independent modifiable risk factor for stroke (Sacco et al., 1997). A two to six fold risk for stroke exists for patients who are diabetic (Flemming & Brown, 2004). Smoking has also been found to be a direct risk factor for stroke. People who smoke 20 or more cigarettes per day have a two to four times increased risk of stroke than non-smokers (Flemming & Brown, 2004). The risk in those who stop smoking declines gradually over a five-year-period and former smokers have no increased risk five years after quitting (Kelly, Pangilinan, & Rodriguez, 2007).

Alcohol consumption can either reduce or increase the risk for stroke depending on the amount of alcohol consumed. Reynolds et al. (2003) asserted that people who drink one to two glasses of alcohol per day had the least risk for ischemic stroke. Individuals who drink more than five glasses of alcohol per day have an increased risk for stroke when compared to people who do not consume alcohol at all.

Cardiac diseases as risk factors for stroke include arterial fibrillation, cardiac failure and coronary heart disease. In the Framingham Study conducted by Wolf, Abbott and Kannel (1991), the incidence of stroke was more than doubled in patients who had coronary artery disease. There was also a four-fold excess of stroke in individuals with cardiac failure and a five-fold excess in those who had arterial fibrillation.

In addition to the above discussed factors, HIV/AIDS is thought be another risk factor for stroke, but has still to be clarified. The occurrence of stroke in patients with HIV infection has been reported mainly in advanced stages of the disease and was generally associated with nonbacterial thrombotic endocarditis, opportunistic infections, or tumors, although a large number of cryptogenic strokes were found, probably related to HIV vasculopathy (Pinto, 2005).

A population-based study in US reported a strong association between AIDS and both ischemic and intracerebral hemorrhagic stroke, with an incidence of stroke in 0.2% of HIV/AIDS patients per year (Pinto, 2005).

In summary, there is evidence from the literature that hypertension, diabetes, smoking, alcohol abuse and cardiac diseases are risk factors for stroke. However, the literature is not clear on the role of HIV/AIDS in stroke epidemiology.

2.4 CLINICAL FEATURES OF STROKE

Clinical features that stroke patients present with are as a result of impairments of body function and structure. These impairments include impaired motor function, abnormal muscle tone, sensory deficits, visuo-perceptual and cognitive limitations, speech deficits, emotional deficits, urinary incontinence and dysphagia (Lawrence et al., 2001; Barker-Collo & Feigin, 2006). Post-stroke patients will therefore have physical, as well as psychological problems.
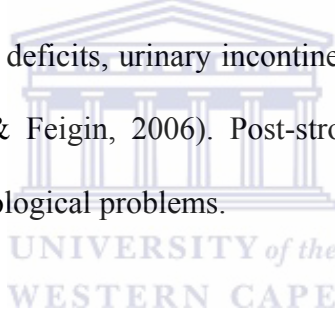
Between 50-70% of stroke survivors deal with residual motor impairments, including loss of strength and dexterity, reduced mobility, poor balance, and muscle weakness (Stewart, Cauraugh, & Summers, 2006). In the population-based study conducted in London on people who had suffered a first ever stroke, Lawrence et al. (2001) found that motor impairment was most common with the upper limb being more affected than the lower limb. The reports on abnormal muscle tone vary across studies as the measurement of muscle tone is subjected to different confounding factors such as recovery stage, time of day, posture, previous handling, and activity (Pomeroy et al., 2000). Sommerfeld, Eek, Svensson, Holmqvist and von Arbin (2004) examined 95

patients with first-ever stroke. In the initial examination (mean = 5.4 days post stroke), they reported flaccidity in 57/95 patients (60%), spasticity in 20/95 patients (21%) and normal muscle tone in 18/95 patients (19%). The examination three months after stroke revealed flaccidity in 46/95 patients (48%), spasticity in 18/95 patients (19%) and normal muscle tone in 31/95 patients (33%).

Another impairment following stroke is loss of sensation. A retrospective evaluation of hospitalized stroke events to describe the clinical characteristics of incident stroke showed that 44.5% of 474 hospitalized patients with stroke presented with some sensory impairment (Rathore et al., 2002). Other studies reported results with higher prevalence of sensory impairment. For instance, a prospective study carried out on 128 admitted stroke patients in Japan, 88.3% of the study participants had sensory disturbance (Isagoda & Nakamura, 1995). Similar results were found in another prospective study conducted in South Korea by Kim and Choi-Kwon (1996) investigating discriminative sensory impairment after stroke. This study included sixty-seven acute stroke patients (within one week of stroke onset) and 85% of the patients were found to have sensory impairment. The fact that the two studies in agreement were prospective employing standardized outcome measures while the study by Rathore et al. (2002) was retrospective using medical records reviews (MRRs) could have resulted in the difference observed in the results.

In a 4-year prospective study conducted in UK by Lawrence et al. (2001) to investigate the prevalence of acute impairments post stroke, it was found that

cognitive impairment was present in 43.9% of the participants. A higher prevalence was reported in a cross-sectional study which was conducted by Saxena (2006) to ascertain the prevalence and baseline determinants of cognitive impairment in stroke patients. This study recruited 252 stroke patients who were consecutively admitted into two rehabilitation hospitals in Singapore during the period from April 2002 to September 2002. It was found that on admission 54.5% of the patients were cognitively impaired. The difference in the reported prevalence of cognitive impairment could be explained as follows: the study conducted by Lawrence et al. (2001) had a bigger sample size of 1259 participants against only 252 participants recruited by Saxena (2006). Such study with a small sample size might give inaccurate results.
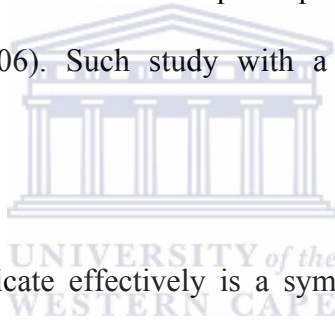
The inability to communicate effectively is a symptom which is present in many stroke patients. Dobkin (2005) said that about 20% of stroke patients have impaired expression and comprehension of language. An evaluation of hospitalized stroke events to describe the clinical characteristics of incident stroke also showed that speech deficits occurred in 24.0% of the hospitalized patients with stroke (Rathore et al., 2002).

Psychological impairments are relatively frequent after stroke. A study conducted by Aybek et al. (2005) to identify emotional behaviors in an acute stroke population over the first seven days following the stroke revealed that 40% of patients showed sadness, 49% passivity, 17% aggressiveness, 53% indifference, 76% disinhibition

signs, 18% lack of adaptation, and 44% denial reaction. In particular, post-stroke depression has been the topic of many studies. In a systematic review of 51 studies reporting prevalence estimates for depression from one week to five years after stroke, the pooled frequency estimate was 33% (Hackett, Yapa, Parag, & Anderson, 2005). Murray, Young and Forster (2007) commented that this is likely to be an underestimate due to the exclusion of selected patient groups (for example those with cognitive impairment and aphasia) from the surveys.

The occurrence of coma has been reported in different studies on stroke. A retrospective study carried out on 228 patients with stroke admitted at the University Hospital of São Paulo from 1989 to 1993 showed that coma was present in 22.4% of cases (Radanovic, 2000). Another prospective study carried out on 148 admitted stroke patients in Gambia showed lower prevalence with only 12% of the patients having coma (Garbusinski et al., 2005).

In addition to the above-mentioned impairments, urinary and fecal incontinence are common in stroke patients. A systematic review of nine studies published between 1985 and 1997conducted by Brittain, Peet and Castleden (1998) investigating the association between urinary and fecal incontinence and stroke revealed that between 32% to 79% of hospitalized patients with stroke experience urinary incontinence at admission and, at discharge, 25% to 28% experience urinary incontinence. Similarly, the prevalence of fecal incontinence in hospitalized patients from two studies published in 1987 and 1997 indicated that between 31% to 40% experience fecal

incontinence on admission, and 18% experience this at discharge (Brittain et al., 1998).

With regard to the affected side of the body, studies across the literature do not agree on the most affected side. For example, Isagoda and Nakamura (1995) found the right side to be the most affected: right side (53.13%), the left side (39.06%) and both sides (7.81). However, Rathore et al. (2002) reported the left side as being more affected: 58% for the left, 39% for the right, and 4 % for both sides respectively. Other studies reported no significant difference between the right and left sides (Jette et al., 2005; Savas, Akkus, Soyupek, Ilgün, & Yildiz, 2007). Jette et al. (2005) in US, for instance, found that out of a sample of 972 stroke patients, 44% had right-sided hemiplegia, 43% of the patients had left-sided hemiplegia and 13% had bilateral involvement.

The conflicting results could be explained by differences in methodology across studies. For example, the study by Isagoda and Nakamura (1995) was hospital-based, prospective and used a sample of 128 participants. The study by Rathore et al. (2002) was community-based, retrospective and used a sample of 474 participants, while the study by Jette et al. (2005) was rehabilitation setting-based, prospective and used a sample of 972 participants.

A systematic review conducted by Barker-Collo and Feigin (2006) investigating the specific areas of neuropsychological deficit to predict functional stroke outcome showed that negative functional outcomes from stroke have been significantly related

to different factors including the affected body side. An individual with left hemiplegia (indicating right hemisphere lesions) would be expected to have a more negative outcome than an individual experiencing a stroke involving the right side of the body (Barker-Collo & Feigin, 2006).

The literature review shows that the most frequent clinical features for stroke result from the impairments of sensation, motor function, cognition, emotional status, urinary control, and speech. However, the studies are not always in agreement with regard to the prevalence rates of those impairments, and this disagreement could be attributed to methodological differences.
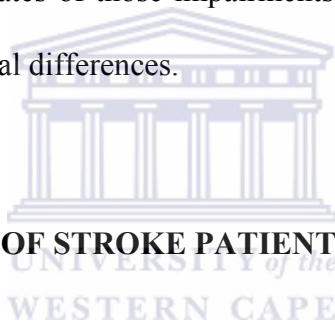
2.5 REHABILITATION OF STROKE PATIENTS

According to Helander (1999), the term "rehabilitation" refers to all measures aimed at reducing the impact of disability for an individual, enabling him or her to achieve independence, social integration, a better quality of life and self-actualization. For the purpose of this study, this section of literature review will be confined to key areas of the process of the rehabilitation of stroke patients including the starting time, length of stay in rehabilitation setting and frequency of rehabilitation.

2.5.1 Starting time of rehabilitation

Studies have indicated that there is a definite positive relationship between the starting time of rehabilitation and the outcome. The sooner rehabilitation is started

post-stroke, the better the functional outcomes will be (Rosenberg & Popelka, 2000). This seems to be related to the fact that in the acute phase the brain is primed for recovery creating an ideal opportunity for therapeutic input (Teasall, Bitensky, Salter, Nestor, & Bayon, 2005). The time for starting post-stroke rehabilitation can be presented in two phases: acute and post-acute rehabilitation phases.

Different clinical trials have showed the benefits of early acute rehabilitation. In the systematic review of stroke unit trials, there was a high degree of consistency in the reporting of policies of early mobilization, usually beginning on the day of admission (Langhorne & Pollock, 2002). Another controlled trial conducted by Musicco, Emberti, Nappi and Caltagirone (2003) recruiting 1716 stroke patients showed that patients who initiated the rehabilitation early (within seven days after stroke) had better long-term outcomes than did those who initiated the rehabilitation after more than one month or from 15 to 30 days after the acute stroke event. However, most patients who suffer a stroke are waiting too long to get to a hospital for care, increasing the risk of serious disability or death (Jacob, 2009). In SSA, patients often present to the hospital more than a month after onset, and many people never present at all, and prefer to go to traditional faith healers (Kengne & Anderson, 2006).

Concerning the post-acute rehabilitation, a study conducted by Paolucci et al. (2000) in Italy to assess the specific influence of onset-admission interval (OAI) on rehabilitation results showed that the short OAI subgroup had significantly higher effectiveness of treatment than did the medium ($p < 0.05$) and the long OAI groups ($p < 0.005$). Beginning treatment within the first 20 days was associated with a

significantly high probability of excellent therapeutic response, and beginning later was associated with a similar risk of poor response (Paolucci et al., 2000). The rehabilitation of stroke patients in developing countries poses a problem as it requires resources not available in those countries. For example, a study done in Abidjan in Ivory Cost has shown that the post-acute rehabilitation begins with an average delay of two months after the stroke (Datié, Nandjui, Manou, Alloh, & Boni, 2006). Another study conducted in Turk has shown that the mean onset-admission interval was 62.9 days (Yavuzer et al., 2001).

2.5.2 Length of stay in rehabilitation setting

The length of stay in rehabilitation hospital varies considerably across studies. For instance, a study conducted in Turk has shown that the mean length of stay in rehabilitation facilities was 97.1 days (Yavuzer et al., 2001). In another study conducted by Jette et al. (2005) investigating the rehabilitation provided to patients with stroke in rehabilitation facilities in US, it was found that the mean length of stay in rehabilitation hospital was 18.7 days. This shorter length of stay observed in US is a result of early discharge supported rehabilitation in which patients are discharged home early from hospital and receive most of their rehabilitation at home (Jette et al., 2005).

A systematic review conducted by Kengne and Anderson (2006) on stroke in SSA has shown that on average, stroke patients stay in hospitals for a period of three weeks. According to Pollack & Disler (2002), clinicians are often pressured (militated

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by a combination of political, financial and clinical determinants) towards discharging stroke patients from the hospital environment as early as possible. They added that however, that is only possible, or safe, when community resources and infrastructure are adequate, and the timing depends as much on such resources as the patient's degree of functional recovery. Successful discharge depends on accurate assessment of the domestic environment, and the establishment of networks to meet critical needs such as personal care, domestic help, home modifications and carer respite.

According to Kwakkel, Kollen and Lindeman (2004), although the literature suggests that increased practice is associated with functional improvement, the actual amount of the time patients spend in active rehabilitation is not enough. For example, in a centre-based observational study conducted by De Wit et al. (2005) in four centers across Europe, findings revealed that the patients spent only from one to three hours per day in therapy, and 75% of the time that patients are admitted is spent in non-therapeutic activities. In developing countries, the situation is likely to be worse as the rehabilitation of stroke requires the resources not available in those countries.

2.5.3 Frequency of rehabilitation

There is evidence that greater frequency of therapy improves functional outcomes (Teasall & Kalra, 2005). Sonoda, Saitoh, Nagai, Kawakita and Kanada (2004) conducted a comparative study of stroke patients admitted to a conventional stroke rehabilitation program five days per week and patients admitted to a full-time

integrated treatment (FIT) program seven days per week. Both groups had similar functional independence measure (FIM) scores at admission; however, the FIT group participants had significantly shorter lengths of stay ($P<0.05$) and were discharged with higher average FIM scores and nearly double the FIM efficiency scores ($P<0.01$). As for the time for starting, the literature suggests that the frequency of rehabilitation of stroke patients is lower in developing than in developed countries. For example, while Jette et al. (2005) found that in US patients received physical rehabilitation on the average number of three physiotherapy sessions per two days, a study done in Abidjan in Ivory Cost has shown that mean frequency of stroke rehabilitation was three times a week, which is the average of one session per two days (Datié et al., 2006).
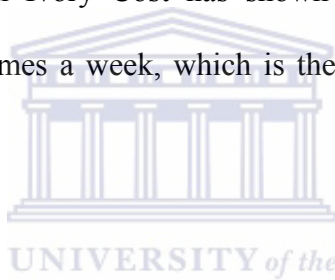
2.6 CHALLENGES EXPERIENCED BY STROKE PATIENTS

Challenges experienced by stroke patients may vary with different stages of the disease, which are the immediate crisis of stroke onset, the acute stage of diagnosis and hospitalization, the stable period of engagement in rehabilitation, and the longer term following discharge to home (Burton, 2000). Kirkevold (2002) explored challenges faced during the different stages of the stroke using interviews. He found that at stroke onset, individuals were challenged by relinquishing control to medical personnel, and viewed stroke as an 'intermission' in life. Once in active rehabilitation, patients became focused on evaluating their progress as they struggled

to make sense of the stroke and its impact. Discharge to home and cessation of rehabilitation were key milestones. In the longer term, adjustment to a new 'normal' self, and dealing with discrepancies between rehabilitation outcomes and recovery expectations were highlighted as critical issues (Kirkevold, 2002).

This part of the literature review will focus on the challenges experienced in post-discharge stage because the period following discharge from hospital or from inpatient rehabilitation is the most challenging for almost all stroke patients (Ch'Ng et al., 2008). This could be associated with a discharge without accurate assessment of the domestic environment, and the establishment of networks to meet critical needs such as personal care and home modifications. The challenges that are experienced by patients with stroke can be classified within the framework of the ICF as activity limitations, participation restrictions and environmental barriers (WHO, 2001).

2.6.1 Activity limitations

Activity limitations are difficulties an individual might have in activities of daily living (ADLs) (WHO, 2001). Within the ICF framework, ADLs refer to mobility, self care and domestic life (WHO, 2001). Mobility activities refer to lifting and carrying objects, walking, moving around using equipment, using transportation and driving (WHO, 2001). Self care activities include bathing, caring for body parts, toileting, and dressing, eating, drinking and looking after one's health (WHO, 2001). Domestic life activities include acquisition of goods and services, preparation of meals, doing

housework like cleaning and assisting others (WHO, 2001).

Mobility difficulties are common among stroke patients. For example, in a study conducted by D'Alisa, Baudo, Mauro and Miscio (2005) exploring the factors determining restricted participation in a selected population of long-term post-stroke survivors, 21.9% of the study sample reported that they were having problems with mobility. This study used structured face to-face interviews, and recruited 73 stroke patients aged from 24 to 83 years, and the duration from the stroke onset ranged from 0.2 to 15 years. A systematic review of 14 studies conducted by Hendricks, van Limbeek, Geurts and Zwarts (2002) investigating motor recovery after stroke also revealed that 20 to 25 percent of all survivors are unable to walk without full physical assistance. Difficulty in walking is a common problem in neurological diseases including stroke, and walking is the activity of daily living on which patients place the most value (Pearson, Busse, van Deursen, & Wiles, 2004). Long-term deterioration of walking ability in stroke patients is regarded as a major problem, as it results in a loss of ADLs independency and social isolation (van de Port, Kwakkel, van Wijk, & Lindeman, 2006).

Using public transportation is a problem among stroke patients. A study conducted by Pajalic, Karlsson and Westergren (2006) showed that out of 89 patients discharged from a stroke unit at a hospital in southern Sweden, at a period of six months post-stroke, 61 participants (69%) had problems or dependency for public transport. In the survey of transport use by stroke patients in the community at one year post stroke,

21/42 (50%) patients responded that they needed assistance to travel, and 22 (52%) reported that they did not get out as much as they wished (Logan, Gladman, & Radford, 2001).

Literature indicates that the activity limitations in self care among stroke patients include bathing, dressing, eating and toilet use. A study on 90 stroke survivors using Barthel Index measurements indicated that at one year after stroke, 32% were dependent when bathing, and 7% were completely dependent for self care (Carod-Artal, Egido, Gonzàlez, & Varela de Seijas, 2000). Another cross-sectional quantitative study conducted by Pajalic et al. (2006) on 89 patients revealed that at six months after stroke the most frequent problems or dependency in self care were for bathing (n = 25), eating (n = 24) and dressing (n=21). Toilet use is another challenge for stroke patients. A quantitative study by Wolfe (2000) revealed that 68% of people with stroke in acute stage compared to 20% at six months are dependent or need help for toilet use at six months post stroke.

Other studies using qualitative methods also reflected self care limitations. In a study conducted to explore subjective accounts of the consequences of stroke using in-depth interviews, interviewees reported a number of ways in which the stroke had affected their ADLs. With regard to self care, the expressed limitations were about bathing and dressing (Pound, Gompertz, & Ebrahim, 1998). Another qualitative study which aimed to investigate stroke survivors' reports of eating-related experiences six

months after stroke revealed that the majority of the study participants had from slight to moderate eating difficulties (Perry & McLaren, 2003).

Beyond mobility and self care, stroke patients also have limitations in domestic life activities. In a study conducted by Mayo, Wood-Dauphinee, Durcan and Carlton (2002) to estimate the extent of activity and participation of individuals six months post-stroke, 54% of the study sample reported limitations in domestic life activities such as housework and shopping. The study conducted by Pajalic et al. (2006) indicated that the most frequent problems or dependency in domestic life among 89 participants were for washing (58/89), cooking (50/89), shopping (50/89) and cleaning (47/89).
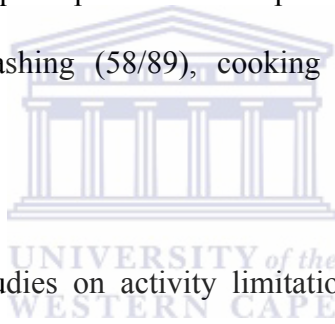
Most of the reviewed studies on activity limitations following stroke have some limitations. For example, participants included in the studies of Mayo et al. (2002), Perry and McLaren (2003), as well as Pajalic et al. (2006) were tracked for no more than six months, and may not reflect important aspects of long-term disability. Kaplan (2005) highlighted that between three and five years many stroke patients experience increasing disability rather than improvement, perhaps due to comorbidity and increasing age. Whilst the studies undertaken by Carod-Artal et al. (2000) and D'Alisa et al. (2005) did include people who had been living with their stroke for one year and 0.2 to 15 years respectively, both studies were quantitative cross-sectional in design. According to Dowswell et al. (2000), quantitative measures may be more

relevant to the concerns of researchers than to those of patients for whom the subjective, lived experience of stroke is likely to be of greater importance.

In summary, the main activity limitations experienced by stroke patients are inability to walk independently, dependence on bathing, eating and dressing, as well as in housework activities such as washing, cooking and cleaning.

2.6.2 Participation restrictions

Participation refers to the ability of the person to manage the role they were previously fulfilling (WHO, 2001). The participation restrictions that are experienced by stroke patients are an inability to return to previous employment, as well as limited involvement in recreational and social activities (Clarke, Black, Badley, Lawrence, & Williams, 1999).

Studies have shown that stroke survivors tend not to return to their previous employment (Saeki, 2000; Vestling, Tufvesson, & Iwarsson, 2003; Saka, McGuire, & Wolfe, 2005). In an international review of 20 studies (Saeki, 2000), return-to-work rates after stroke ranged from 7% to 84%. In a Swedish study, Vestling et al. (2003) recruited 120 stroke patients over a four-year period to investigate the returning to work at six months post stroke. Of the 120 study participants, only 41% returned to work and the mean time to return to work was approximately one year and of those who returned, just over half had significantly reduced working hours.

In the same study, Vestling et al. (2003) also identified factors that predicted return to work. Using multiple logistic regression analysis they found that those who could walk independently, had a non manual job, and had preserved cognitive abilities, were more likely to return to work (Vestling et al., 2003). Although retrospective and limited by the fact that participants were recruited from a limited geographical area (the Swedish city of Malmo) and varied greatly in their time since stroke, this study highlights some important factors (mobility, job type and cognition) affecting return to work success, which may need to be addressed in stroke vocational rehabilitation.

People who cannot return to work or re-train may face a lifetime of unemployment and dependence on the families and state (Radford & Walker, 2008). The resultant economic impact in terms of lost productivity and income is huge with stroke survivors consuming an estimated £689 million in benefits alone each year in UK (Saka et al., 2005). Thus, for many, the ultimate goal in stroke rehabilitation is to return to work, regain (financial) independence and rebuild confidence (Stroke Association, 2006).

Social isolation is a common finding in the studies on stroke survivors and community participation. A systematic review conducted by Salter et al. (2008) revealed that the majority of participants across studies appeared to experience feelings of increasing social isolation, social withdrawal and/or altered relationships with both families and friends. This review involved nine qualitative studies and aimed to explore the experience of living with stroke. Participants in a qualitative

study conducted by Burton (2000) referred isolation as to feeling as though they were isolated or stuck in a cage: the cages ranged from their bodies, to the hospital and their homes. It is also reported that all references to this were accompanied by feelings of frustration and anger. Waiting appeared to be a key feature of this isolation; waiting for help, waiting for family and friends to come (Burton, 2000). Loss of social relationships has also been found in a study conducted by Pound et al. (1998) to explore the subjective accounts of the consequences of stroke. The authors reported that the stroke survivors had problems in their relationships with spouses and other family members. Increased social isolation of stroke survivors has been found to contribute to reinforcement of a sense of loss and depression (Clark & Smith, 1999).
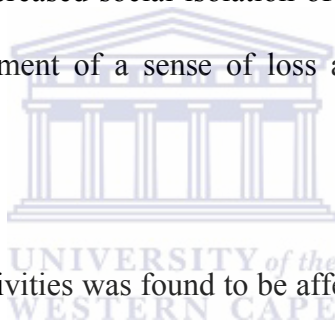
Participation in leisure activities was found to be affected by stroke. In the qualitative study conducted in London by Pound et al. (1998), the participants described the disadvantage they experienced as a result of not being able to pursue their old leisure activities. Within the sample, the leisure activities people had previously enjoyed were diverse and included dancing, knitting, travelling, reading, going out for a stroll and watch the sports on television (Pound et al., 1998). Another qualitative study using focus group discussions to explore the challenges stroke sufferers face over time during recovery revealed that a great distress among the participants was associated with the loss of hobbies and activities that had previously been a source of pleasure and achievement (Ch'Ng et al., 2008). These findings were consistent with the findings from a quantitative study assessing the rehabilitation needs, level of

disability, health-related quality of life, and satisfaction in various life situations of stroke patients in Sweden. It was found that more than 50% of the participants were not satisfied as they were no longer involved in leisure activities (Nilsson, Aniansson, & Grimby, 2000).

2.6.3 Environmental barriers

Some environmental factors affect ADLs and social participation after stroke. Rather than helping, these factors can hinder the accomplishment of daily activities and social roles (Vincent et al., 2007), and hence being regarded as barriers. As mentioned by Hare, Rogers, Lester, McManus and Mant (2006), the literature concerning environmental barriers experienced by stroke patients is limited. Traditionally, most environmental interventions are limited to considering architectural barriers in the individual's home but many other physical and social factors might determine how a person will carry out his/her daily activities (Rochette et al., 2001). The findings from the few related studies can be divided into physical, social and attitudinal environmental barriers.

2.6.3.1 Physical environmental barriers

Physical environmental barriers refer to obstacles in natural or technological elements (Vincent et al., 2007). Physical environment issues such as inaccessible entryways, bathrooms, and transportation systems, with key barriers including door thresholds

and lack of handrails are barriers to community participation in survivors of stroke (Hammel, Jones, Gossett, & Morgan, 2006). Negotiating stairs and narrow doorways have also been identified as major barriers to role performance in the home for stroke survivors (Reid, 2004a). A related study explored how older adults with stroke rate the accessibility of their housing environments (Reid, 2004b), and overall, participants reported that the design of their homes allowed them to manage self-care activities but not all household activities. For many individuals, the outside of the home posed barriers to occupational performance, with key issues including uneven ground, poor lighting, and stair access (Reid, 2004b). For others, physical space within the home was a problem with many persons unable to maneuver small areas with assistive devices (Reid, 2004b). Given the well-documented physical barriers to participation and performance in everyday life, it is important to assess and modify the physical environment in rehabilitation of people with stroke.

2.6.3.2 Social environmental barriers

Social environmental barriers include obstacles in elements such the social support from the family and utilization of health and social services (Vincent et al., 2007). The reported barriers in the social environment in the study conducted by Ekstam, Uppgard, von Koch and Tham (2007) were having little social support from friends owing to stroke-related disability and having a limited social network. According to Chau, Woo and Chang (2007), social support for stroke patients, whether the support is emotional, informational, instrumental or appraisal, has a positive influence on a

stroke patient's functional and psychosocial recovery. Therefore, lack of social support as experienced by stroke patients would have a negative impact on the psychosocial recovery and reintegration post-stroke.

In addition to the above-mentioned barriers, discharged stroke patients face a challenge to continue rehabilitation.   In a qualitative study conducted by Ch'Ng et al. (2008) exploring the challenges stroke sufferers face over time during recovery, the participants described a sense of abandonment by the medical system, associated with concern that they had exhausted the limits of available help but were not 'back to normal'.

2.6.3.3 Attitudinal environmental barriers

Attitudinal environmental barriers to stroke patients include negative behaviors such as stigma. Stigma towards stroke patients was found in a qualitative study conducted by Hare et al. (2006) to explore the needs of patients with stroke and their families. The study used focus group discussions involving 82 stroke patients from seven practices from South Birmingham Primary Care Trust in the UK. A number of participants said that they tended not to tell anyone about their stroke unless they were family members or close friends because of perceived stigmatizing responses (Hare et al., 2006). Negative attitudes of existing employers, or prospects for securing new employment were also perceived as a problem, particularly for the younger patients (Hare et al., 2006).

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2.7 SUMMARY OF THE CHAPTER

From reviewing the literature, it is clear that stroke is a condition that is mainly caused by cerebral infarction. It affects the elderly, although it can affect people of all ages, and a clear picture is available of the extent of the condition as it affects populations globally. More epidemiological studies are however needed in Rwanda and other developing countries to ascertain the exact status of the disease in these countries. The main clinical features and risk factors for stroke have been well-established in various studies. The literature is also clear about the positive effects of early and intensive rehabilitation of stroke patients. Many authors recognize that the effect of stroke goes beyond the difficulties with movement, and they highlight that self care and household activities also become difficult following stroke. Furthermore, the stroke patients face problems related to employment and social contacts. Some environmental factors have been found to interfere with activities and social participation of the stroke patients: inaccessible physical environment, lack of social support, abandonment by the medical system and stigma.

CHAPTER THREE: METHODOLOGY

3.0 INTRODUCTION

In this chapter, the researcher provides a description of the study setting for both the quantitative and qualitative phases of the study. The researcher also presents the methods used in the study. The study design, study population, sampling method and instrumentation are described. The procedure of data collection and how data analysis was carried out is explained. At the end, the ethical considerations pertaining to the study are given.

3.1 STUDY SETTING

The study setting for the quantitative phase of the study was the Ruhengeri Hospital, while the study setting for the qualitative phase was the Musanze District. The Ruhengeri Hospital is a district hospital, located in Musanze District, in the Northern Province of Rwanda. The Ruhengeri Hospital is 60 miles away from Kigali, the Capital of Rwanda. It has a capacity of 409 beds serving about 400,000 people who reside mainly in the Musanze District. The hospital comprises different departments, which include Emergency, Surgery, Maternity, Intensive Care Unit, Internal Medicine, Pediatrics, Pharmacy, Physiotherapy, Orthopedics, Radiography (X-rays only), Dentistry, Ophthalmology, Laboratory, Central Records and Administration departments. The hospital staff includes 202 people including 21 doctors, 97 nurses, four physiotherapists and others. Only doctors, nurses, physiotherapists and social

workers are involved in stroke rehabilitation. The Physiotherapy department manages about 40 outpatients per day in addition to hospitalized patients from Surgery, Maternity, Intensive Care Unit, Internal Medicine, and Pediatrics departments.

The Ruhengeri Hospital receives on average five stroke patients per month. Stroke patients are admitted into the Intensive Care Unit or the Internal Medicine. The rehabilitative care, which is provided by the physiotherapists, is aimed at improving the patient's functional status. Rehabilitation includes individual treatments only. There is neither outreach nor community-based rehabilitation services that are provided to stroke patients and these patients get institution-based rehabilitation services only as inpatients or outpatients.
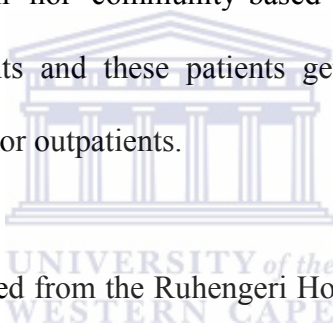
All interviewees, discharged from the Ruhengeri Hospital, lived in Musanze District, an area which is mainly rural, and where at least 91% of the population is engaged in agriculture (Musanze District, 2009a). Musanze District has a total population over 380,000 having the highest density in the country: 770 persons per km^2 (Joint Technical Mission, 2007). Most families (about 65%) live below poverty line (Musanze District, 2009b). In addition, many families have been destroyed by the 1994 genocide and the repetitive 1997-1998 wars in the region, leaving survivors with disabilities, widows and orphans. Musanze is the most mountainous district in Rwanda (Karabayinga, 2009), and there is therefore difficult geographical access and transport.

3.2 STUDY DESIGN

A Concurrent Mixed Model Design was used to collect data. According to Tashakkori and Teddlie (2003), a Concurrent Mixed Model Design is a mixed methods design in which there are two relatively independent phases: one with quantitative question(s), data collection and analysis techniques and the other with qualitative question(s), data collection and analysis techniques.

The quantitative method was found more appropriate to answer the first research question as the purpose of the quantitative method is to describe, explain or predict phenomena (Domoholdt, 1993). In this study, the phenomena refer to the profile of stroke patients admitted at Ruhengeri Hospital from 2005 up to 2008. The qualitative method was found more appropriate for the second research question as qualitative research is grounded in a concern with people's everyday realities, seeking to understand how people experience and make sense of their lives following a devastating event such as a stroke (Hammell, Carpenter, & Dyck, 2000). The use of qualitative methods provides participants with opportunities to tell their stories outside the boundaries of structured measurement scales, thus bringing depth and clarity to the understanding of post-stroke recovery (Green & King, 2009). A quantitative retrospective approach was used to collect information regarding the profile of stroke patients admitted at Ruhengeri Hospital from 2005 up to 2008. The retrospective approach uses existing sources such as medical records to obtain data (Hess, 2004).

Existing patients' records were reviewed to collect information related to demographic characteristics, medical characteristics, stroke onset-admission interval, the length of hospital stay, and the process of physiotherapy for the stroke patients admitted at Ruhengeri Hospital. Although medical records reviews (MRRs) are usually retrospective and the reviewer cannot obtain clarification of missing or ambiguous data (Banks, 1998), the quality of the data gathered from MRRs studies is not necessarily always inferior to prospectively collected information (Worster & Haines, 2004).

A qualitative phenomenological approach was used to collect information regarding the challenges experienced by stroke patients admitted at Ruhengeri Hospital. The purpose of the phenomenological approach is to 'give voice' to the person being studied, and requires that the researcher presents the subject's view of his or her world (Holstein & Gubrium, 1994). This approach has assisted in identifying the challenges experienced by the stroke patients from their own point of view.

3.3 STUDY POPULATION AND SAMPLING

3.3.1 Study population

The study population consists of all stroke patients admitted at Ruhengeri Hospital in Rwanda.

3.3.2 Sample for the quantitative phase of the study

All medical records of stroke patients admitted at Ruhengeri Hospital between January 1st, 2005 and December 31st, 2008 were reviewed to collect information related to demographic and medical characteristics, as well as the stroke onset-admission interval, the length of hospital stay, and the process of physiotherapy for the stroke patients admitted at Ruhengeri Hospital. According to Worster and Haines (2004), a common method of sampling in medical records review is to select all of the consecutive cases within a given time frame. This type of convenience sampling is an acceptable approach provided the period is long enough to include seasonal variations or other changes over time that are relevant to the research question (Hulley et al., 2001).
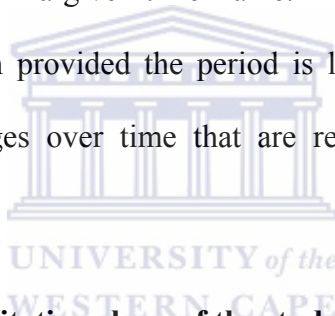
3.3.3 Sample for the qualitative phase of the study

After identification of stroke patients admitted at Ruhengeri Hospital between January 1st, 2005 and December 31st, 2008, a sub-sample of 10 individuals discharged was selected from the quantitative sample to form the study sample for the qualitative phase. Stroke patients in post-discharge stage were targeted because the period following discharge from hospital or from inpatient rehabilitation is the most challenging for almost all stroke patients (Ch'Ng et al., 2008). The sampling procedure was mainly purposive, as the aim was to capture a sufficiently wide range of patient views.

According to De Vos (2002), purposive sampling is based on the judgment of the researcher, in that a sample is composed of elements that contain the most characteristic, representative or typical attributes of the population. Characteristics that were considered for the purposively selection were the current age, gender, chronicity of stroke, and independent walking. These characteristics were found to be significantly related to positive or negative adjustment and development of self-concept post-stroke (Stuifbergen, 1995), and would contribute to a richer variation of the phenomena under study (Graneheim & Lundman, 2004).

The current age was calculated as a summation of the patient's age at the time of admission and the period post admission until the time of data collection. The chronicity of stroke was calculated as the difference between the date of data collection and the date of stroke onset. After that, a list of all the patients forming the quantitative sample and discharged alive was compiled with their gender, current age and chronicity of stroke. Firstly, all patients were divided into two groups according to gender, meaning female group and male group. Secondly, in each gender group, the patients were put in ascending order according to their current ages. Thirdly, every patient was assigned his/her chronicity of stroke. The patients with the same current age were put in ascending order according to their chronicities of stroke. The patients on the list and who were convenient to the researcher were visited and assessed for independent walking. Then a purposive sample of 10 participants with different characteristics and accessible to the researcher was selected.

Figure 3.1 summarizes the process of selection of the sample for the qualitative phase and details about the recruited subjects are given in table 6.1.
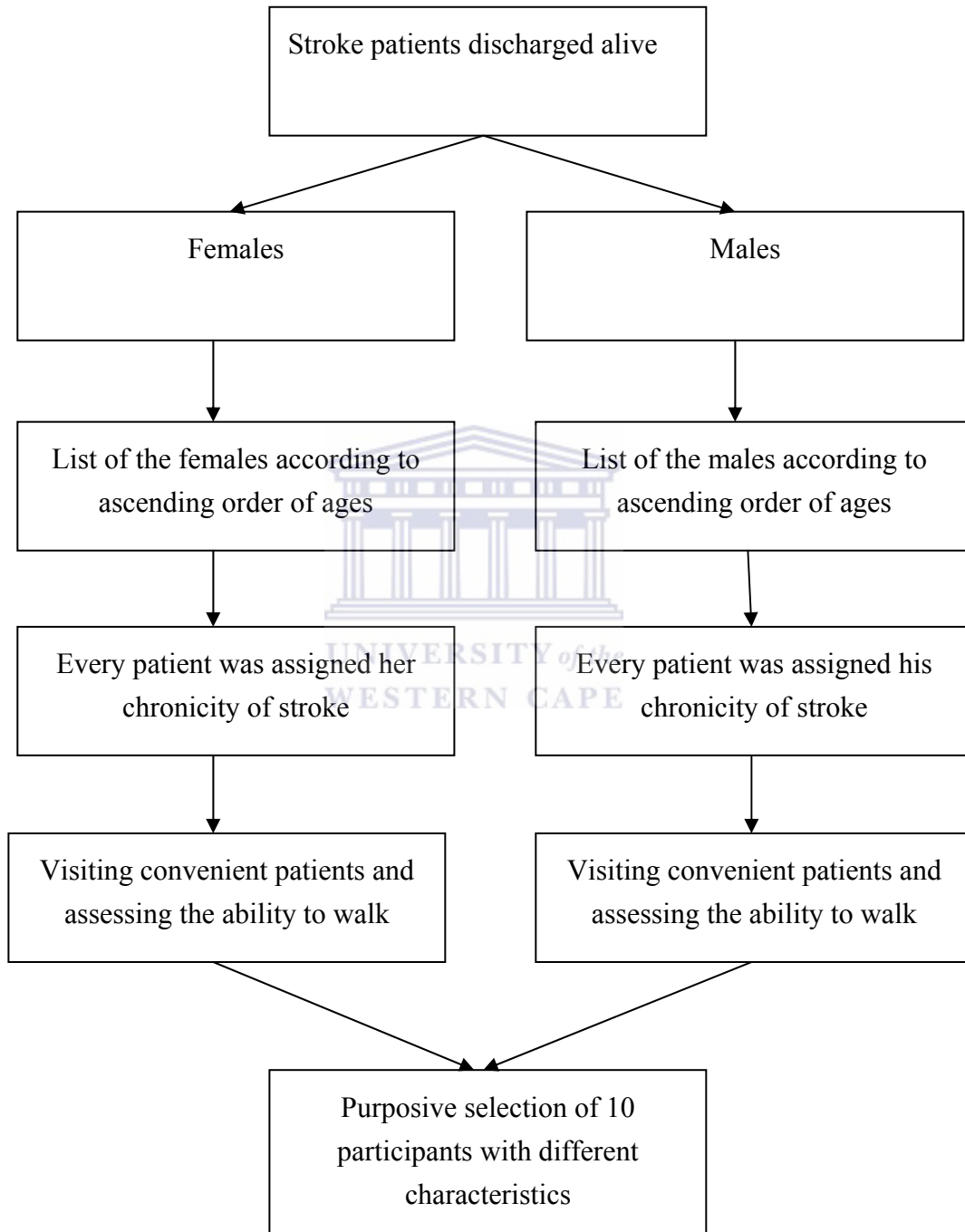
Figure 3.1 Process of selection of the sample for the qualitative phase

3.3.4 Inclusion and exclusion criteria

a) For the quantitative phase of the study, stroke as the definite diagnosis confirmed by a medical doctor, was the sole inclusion criterion to select study cases for medical records review. Thus, cases where stroke was associated with other hypotheses like seizures, encephalitis, hepatic encephalopathy, cardiac failure or brain tumor were excluded.

b) For the qualitative phase of the study, patients who still needed assistance at least for one activity were included. On the other hand, it was necessary to recruit subjects who were able to articulate their experiences and feelings, and accordingly exclude individuals with communication or cognition problems. To obtain respondents with experiences related to stroke, individuals who had suffered other major diseases after the initial stroke were excluded (for example head injury, osteoarthritis, rheumatoid arthritis).

3.4 STUDY INSTRUMENT FOR QUANTITATIVE PHASE OF STUDY

A data gathering instrument (Appendix A) was used to collect information concerning demographic characteristics, medical characteristics, stroke onset-admission interval, the length of hospital stay, and the process of physiotherapy for the stroke patients admitted at Ruhengeri Hospital.

3.4.1 Development of data gathering instrument

A data gathering instrument was developed because no standardized instrument that met the specific needs of this study could be found. The data gathering instrument was developed by the researcher based on the study objectives, the literature (Kaplan, 2005; Pollack & Disler, 2002; Stuifbergen, 1995; Vestling et al., 2003), and the researcher's experience. The literature used to formulate the data gathering instrument is included below according to the three sections of the instrument. The researcher's first step in developing the data gathering instrument was to draft items for consideration for inclusion in the instrument. Before writing any items, the researcher reexamined the objectives of the current study and outlined the major sections the data gathering instrument needed to include to answer the first question under study. The final data gathering instrument comprised three main sections: demographic data, medical data, and rehabilitation data.

SECTION A: DEMOGRAPHIC DATA

Section A addressed the first objective of the current study and included the following demographic items: age, gender, marital status and occupation. These items were developed from measurements by Stuifbergen (1995), who indicated that demographic characteristics include age, gender, marital status and employment status.

i. Age

According to the literature, age has been found to be a definite risk factor for stroke incidence and mortality, the risk of stroke incidence and mortality increasing with an increase in age (American Heart Association, 2001). In addition, age was found to be associated with functional outcome post stroke. Younger patients have better survival and early and long-term outcomes (Musicco et al., 2003). The patient's age at the time of admission was either recorded as documented or calculated from the patient's date of birth.

ii. Gender

Gender was also found to be associated with stroke incidence and mortality, the risk of stroke incidence and mortality being higher in male gender (American Heart Association, 2001).

Gender was included to assess whether the research population consisted of more males or females.

iii. Marital status

The literature suggests that there is relationship between the marital status and functional outcome as well as the challenges experienced following stroke, stroke survivors living alone being at risk of poor functional outcome (Nilsson et al., 2000). Information on the marital status of the patients was obtained as documented in a patient's medical record to identify how many persons were single and how many were widowed which could be problematic if there was reliance on a care-giver and social support.

iv) Occupation

According to Saeki, Ogata, Okubo, Takahashi and Hoshuyama (1993), prior occupation status has more powerful effect on return to work post-stroke than the educational level. It was found that non manual occupations were associated with increased return to work (Vestling et al., 2003). Information regarding the occupation status pre-stroke would give an indication of the return-to-work challenge post-stroke. The information on occupation was collected as documented in patients' files.

SECTION B: MEDICAL DATA

Section **B** addressed the second objective of the study and consisted of two parts comprising items reported on admission or during hospitalization. Those parts were: clinical features and risk factors for stroke.

B1. Clinical features

Different studies have revealed a number of stroke clinical features. It was therefore considered important to collect data regarding the common clinical features including the stroke type, occurrence of coma, cognitive impairment, vision impairment, speech impairment, emotional impairment, muscle tone impairment, side of body impairment, incontinence and sensation impairment. These items were developed from the literature indicating that they are common in stroke patients and have an impact on survival, functional outcome, ADLs and participation (Kaplan, 2005).

The type of stroke was included to assess the proportion of the hemorrhagic type as the literature suggests that the mortality rate for hemorrhagic strokes is higher compared to ischemic strokes (Rosamond et al., 1999; Fang et al., 2004). The ischemic type, hemorrhagic type or association of both types were recorded if they had been documented in the patient's medical record.

Other clinical features were recorded as present (Yes) or absent (No) either as documented in records, or after analysis and interpretation of documented clinical data related to those clinical features. A clinical feature which was present on admission or occurred during admission and then resolved during the admission was also recorded as "Yes". A clinical feature was considered as missing if there was neither documentation nor clinical data about it. As suggested by Worster and Haines (2004), the following definitions of the clinical features were applied for the interpretation of the documented clinical data:

Coma: a state of deep unconsciousness when the person is not responsive or able to be aroused (Stroke education, 2006). This was only recorded if documented.

Cognitive impairment: a disorder encompassing problems in several areas (Morris, 2008) including:

- ➤ Difficulty concentrating or paying attention

- ➤ Memory loss of difficulty remembering things

- ➤ Problems with comprehension or understanding

➢ Problems with judgement or reasoning

➢ Confusion/Orientation deficit

Cognitive impairment was recorded as "Yes" if one of the above problems was documented.

Vision impairment: following stroke there are three main problems that can affect vision (Morris, 2008).

➢ Hemianopia: the loss of half of the visual field in each eye

➢ Diplopia: double vision

➢ Visual inattention/neglect

Speech impairment: difficulty making and coordinating sounds and/or the individual having difficulty making a smooth transition between sounds and words (Morris, 2008).

Emotional impairment: behavioural changes such as irrational behaviour, mood swings, inappropriate anger or crying and socially inappropriate behaviour (Morris, 2008).

Muscle tone impairment:

➢ **Spasticity:** also known as muscle hypertonicity, manifested by increased resistance to stretching and heightened reflexes (Gregson et al., 2000).

➢ **Flaccidity:** absence of muscle tone, flabby or floppy muscles (Stroke education, 2006).

Side of body impaired: The side(s) of body impairment for each patient was recorded as documented to see how the body sides in stroke patients admitted at Ruhengeri Hospital were affected, compared to what has generally been reported in the literature.

Incontinence: inability to control urinary bladder (urinary/bladder incontinence) or bowel functions (bowel incontinence), or both (Stroke education, 2006).

Sensation impairment: This may be described as numbness, marked tingling, or abnormal sensation (ARIC Project, 2005). Other synonyms include: hemianesthesia, parasthesias, analgesia (ARIC Project, 2005).

B2. Documented risk factors for stroke

Many epidemiological studies have revealed a number of risk factors associated with stroke. It was therefore considered important to collect data regarding the documented risk factors when compiling a profile of stroke patients. The following risk factors (found to be most common in stroke populations) were collated if these had been documented: hypertension, diabetes, cardiac failure, atrial fibrillation, TIA, previous stroke, smoking and HIV. Synonyms for "TIA" may include: acute cerebrovascular insufficiency, spasm of cerebral arteries, insufficiency of basilar, carotid, or vertebral arteries, or neurological deficit lasting less than 24 hours (ARIC Project, 2005). It is important to notice that risk factors were noted if the information had been recorded in the patient's medical records. It was therefore possible that risk factors, if present, may have not been recorded for some patients.

SECTION C: REHABILITATION DATA

Section **C** addressed the third and fourth objectives of the study and included items regarding the stroke onset-admission interval, length of hospital stay, receiving physiotherapy and, if the patient had received physiotherapy, time of commencement of physiotherapy since admission, duration of physiotherapy and the total number of physiotherapy sessions.

i. Stroke onset-admission interval

Excessive delay between the date of incident and initiation of rehabilitation negatively affects the outcome of rehabilitation (Hoening, Horner, Duncan, Clipp, & Hamilton, 1999). The stroke onset-admission interval was therefore recorded to see if it corresponds to the recommendations. This interval was either documented or calculated as the difference between the date of stroke onset and the date of admission.

ii. Length of hospital stay (LOS)

The LOS was calculated as the difference between the date of admission and the date of discharge, and was recorded to see whether the LOS at Ruhengeri Hospital exceeded or was less than what has generally reported in the literature. If the patient died, then the date of death was considered as the date of discharge. The researcher investigated if there was correlation between the LOS and the number of physiotherapy sessions.

iii. Receiving physiotherapy

Literature suggests that physiotherapy treatment was found to be associated with the better functional outcome (Wiles et al., 2004). By recording if the stroke patients received physiotherapy treatment, the involvement of physiotherapists in a team management of stroke patients at Ruhengeri Hospital could be determined. Such information was noted if the physiotherapist had reported his/her services in the patient's medical records. It was therefore possible that some patients may have not been recorded as having received physiotherapy if the physiotherapist did not note anything about the services he/she provided to the admitted stroke patients.

iv. Time of commencement of physiotherapy since admission

Extensive studies have confirmed that physiotherapy interventions are one of the most effective forms of post-stroke rehabilitation, and this is true particularly if such interventions are started soon after the initial stroke (van Peppen et al., 2004). The researcher therefore needed to know how soon, following their stroke, patients were treated by physiotherapists at the hospital. The time of starting physiotherapy after admission was calculated as the difference between the date of the first physiotherapy session and the date of admission.

v. Duration of physiotherapy

According to Pollack and Disler (2002), rehabilitation after stroke is a continuum, starting within days of stroke onset and ending only when it no longer produces any positive effect. The duration of physiotherapy for each patient was recorded to see

whether the duration of physiotherapy at Ruhengeri Hospital exceeded or was less than what has generally been reported in the literature. This duration was calculated as the difference between the dates of the first and the last physiotherapy sessions.

vii. Total number of physiotherapy sessions

Although the existing evidence regarding intensity of therapy indicates that greater intensities of treatments result in improved short-term functional outcomes, it was found that the rehabilitation staff does not provide the intensity and frequency of therapy needed to obtain the improved outcomes (Teasall & Kalra, 2005). The total number of physiotherapy sessions per individual was recorded to determine how often stroke patients at Ruhengeri Hospital use the services of the physiotherapist comparing to other reports in the literature.
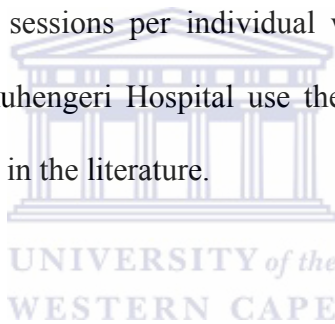
3.4.2 Validity of data gathering instrument

After the draft of the data gathering instrument was compiled, it was subjected to a peer review, by the study supervisor and colleagues knowledgeable in the field of stroke profile, as this is essential for content validity (Domoholdt, 2000). Suggestions were considered to make changes before proceeding to the main research. One suggestion was to use the code "99" (Banks, 1998) in cases where the desired data was "missing" from the records, rather than leaving the response fields blank. In section C, a question "has the patient received physiotherapy after admission" was included in the instrument. Then if the answer was "Yes", the following items
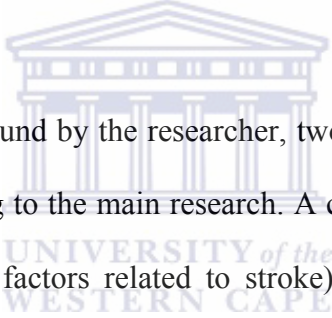
regarding the time of commencement of physiotherapy since admission, the duration of physiotherapy and the total number of physiotherapy sessions were recorded. If the answer was "No", the following items were skipped and filled in by the data abstractor with the code "88" for "Not applicable" (Banks, 1998).

3.4.3 Reliability of data gathering instrument

After the research assistant was trained as described in section 3.5.1, the inter-rater reliability test of data gathering instrument was done by collecting data from 15 patients' records by the researcher and the research assistant separately, to test for any variations in the data recording. Cohen's kappa (k) measure was then used to determine the inter-rater reliability coefficient. According to Worster and Haines (2004), Cohen's kappa (k) measure has an advantage to be interpreted as the extent of agreement achieved compared with the total amount of agreement possible beyond chance agreement. The inter-rater reliability coefficient was between 0.84 and 0.94 for the different sections of the data gathering instrument (mean = 0.90). This coefficient was good. According to Worster and Haines (2004), it is generally recommended that researchers strive to achieve a minimum level of inter-rater agreement of 60% beyond chance agreement, which is a kappa value of 0.60 or greater.

3.4.4 Pilot study

A pilot study was carried out to pre-test the data gathering instrument on ten patients' records at the Ruhengeri Hospital. The aim of the pilot study was to assess if the instrument's items follow the order in which the information appears in the patients' records. It also assessed if the terminologies of the instrument were consistent with those found in the records. The pilot study also assisted to determine the adequacy of the research process as suggested by van Teijlingen and Hundley (2001) for possible changes before it was used.

Following the problems found by the researcher, two changes were made in sections B and C before proceeding to the main research. A change was made in section B of the instrument (B2: Risk factors related to stroke): the item "alcohol abuse" was removed as in the medical records there was no distinction between "alcohol use" and "alcohol abuse". In section C, the item of physiotherapy frequency per week was also removed as it varied with different treatment weeks for a patient, and some patients had physiotherapy only once during their admission. The item of "Frequency of physiotherapy" was replaced by "Total number of physiotherapy sessions" received by each patient.

3.5 PROCEDURE OF DATA COLLECTION

After obtaining the permission to conduct the study as described in the section on ethical considerations (3.7), data was collected in two phases: quantitative phase and qualitative phase.

3.5.1 Quantitative data collection

A research assistant was recruited to assist the researcher with data collection. After the recruitment, the following data extraction strategies were used in order to avoid bias and increase inter- and intra-rater reliability:

1. The research assistant had enough training and practical sessions before starting data collection. During the training process, the researcher and the research assistant discussed the data elements, their translations in French (as some medical records were in French), their location in the medical records, and their various synonyms and abbreviations, as suggested by Banks (1998). Before the research assistant could begin the collection of quantitative data for the study, three 'practice' data gathering instruments were completed using patients' records. The researcher then checked to ensure that the data gathering instruments were completed correctly.

2. The research assistant was advised at the beginning that his work will be checked for accuracy (Worster & Haines, 2004).

3. It was established that missing, ambiguous and conflicting data will all be coded as "missing" (Wu & Ashton, 1997; Worster & Haines, 2004).

The quantitative data collection was multi-staged:
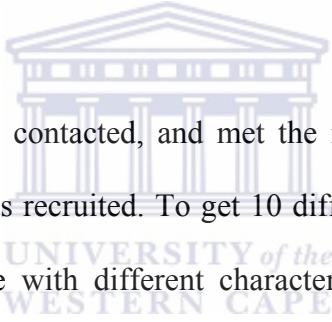
Stage 1: Identification of stroke patients: this identification was obtained from register books in departments where stroke patients were admitted. After identifying stroke as the final diagnosis of a patient and confirmed by a medical doctor, we continued with the identification including the surname, the first name, the patient's folder number, the date of admission, the date of discharge, the status at discharge (dead or alive) and the address. It was necessary to identify those elements for searching patients' records at the central records department and the physiotherapy department, and for the selection of the interview participants.

Stage 2: Identification of records: it was done by hand-searching of patients' records using the list compiled. The records were searched at the central records department in places reserved for the medical records from the internal medicine and intensive care unit departments. In order to get information related to physiotherapy of stroke patients, the physiotherapy records were identified in physiotherapy department as it is where they are kept.

Stage 3: Records' data extraction: using a data gathering instrument and with respect to the data extraction strategies described earlier, the researcher and research assistant proceeded to collect the quantitative data from patients' records. They took care such that no patient's record was duplicated during data collection.

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3.5.2 Qualitative data collection

Interviews were conducted with nine participants in their own homes and one participant at the hospital. Patients who were interviewed for the qualitative phase of the study were purposively selected as indicated in section 3.3.3. The researcher contacted the 10 purposively selected patients who met the inclusion criteria to obtain their consent and willingness to participate in the study. The researcher got access to them for an interview at their homes with the guidance of their addresses identified in stage 1 of quantitative data collection.

The first patient who was contacted, and met the inclusion criteria, and agreed to participate in the study was recruited. To get 10 different participants, other patients were contacted, and those with different characteristics under consideration were recruited. When inviting the respondents to participate in the study, it was emphasized that the purpose of the interview was to explore the patients' experiences of how the stroke had impacted on their lives from their perspectives, rather than conducting a clinical assessment. All contacted subjects agreed to take part in the study and were willing and appreciative of the opportunity to relate their experiences. A convenient time and location was determined for the patient interviews, and the interviews lasted on average fifty minutes. The rooms where the interviews were conducted were assessed prior to commencing to ensure good quality recordings and without possible interruptions and distractions.

Face-to-face interviews in Kinyarwanda were used to provide in-depth descriptions of the informants' challenges. The value of face-to-face interviews is that the researcher can achieve a greater depth of response, maintain control over who actually responds, and determine the opinions of those who cannot read or write, and have higher response rates (Domholdt, 2000). All interviews were conducted by the researcher. The interviews were guided; an interview guide (Appendix B) was developed on basis of the fifth study objective, the literature, together with the researcher's experience. This interview guide was translated from English to Kinyarwanda (Appendix C) as the participants were more fluent in Kinyarwanda. Within this frame, the structure of the interviews was designed to be free and open.

The relevance, acceptability and clarity of the questions were constantly considered during the conduct of the interviews. During purposeful conversations, information was sought from patients on their challenges experienced. The interviews started with a 'grand tour' question to set the tone of the interview, and to let the participants determine what was important for them to tell about living with a long-standing disability (Stuifbergen & Rogers, 1997). Therefore, participants were asked to tell the story of their stroke and the way it had affected their lives, beginning with the question: "Please tell me about any problems you are having since you got stroke". The remainder of the interview guide consisted of a series of guided probes that endeavored to obtain an in-depth description of the challenges experienced. All interviews were audiotape-recorded, and the research assistant took field notes.

3.5.3 Trustworthiness of the qualitative data

To establish trustworthiness of the qualitative data, Shenton (2004) suggested the concepts of credibility, confirmability, transferability and dependability as essential decisive factors for quality in qualitative research. To enhance the four criteria, different strategies were employed.

To enhance credibility of the qualitative data, the themes presented were illustrated with representative quotations from the transcribed texts (Graneheim & Lundman, 2004). To ensure confirmability of the qualitative data, a peer examination was used by the researcher discussing the research process and findings with colleagues and experts who have experience in qualitative research methods. For the same purpose, the study supervisor went through field notes and transcriptions, data reduction and analysis products (condensed notes), data reconstruction and synthesis products (thematic categories, interpretations) (Lincoln & Guba, 1985).

To enhance transferability of the qualitative data, a clear and distinct description of the study setting, the selection and characteristics of participants, data collection and process of analysis was used (Graneheim & Lundman, 2004). For this purpose, different characteristics that were considered to select informants included chronicity of stroke, gender, current age, and functional status (independent walking) as indicated in section 3.3.3. To address the dependability of the qualitative data, the researcher has used a code-recode procedure during data analysis as suggested by

Krefting (1991).

3.6 DATA ANALYSIS

3.6.1 Quantitative data analysis

In case of items (variables) recorded as missing in less than 10% of the participants in total, the participants with such missing items were excluded from the analysis (case deletion) (Worster & Haines, 2004). Case deletion is the most commonly used method and involves simply omitting subjects with missing values from the analysis (Worster & Haines, 2004). For the items recorded as missing in 10% or more of the participants, those items were not included in data analysis (Wu & Ashton, 1997; Worster & Haines, 2004).

The SPSS (16.0 version) and the Microsoft Excel Package 2007 were used to analyze the quantitative data. Based on the descriptive nature of the study, the data analysis included descriptive statistics as frequency distributions and percentages.

The range, mean and standard deviations were used for the age, stroke onset-admission interval, length of hospital stay, duration of physiotherapy and number of physiotherapy sessions. The data was presented in the forms of normal tables and cross-tables, and graphs. Chi-square test was used to test for significant relationships

between variables: gender versus age group; marital status versus gender; and LOS versus coma. A Pearson correlation test between the number of physiotherapy sessions and the LOS was done. The significance level was set at $p < 0.05$ for all tests.

3.6.2 Qualitative data analysis

The tape-recorded interviews in Kinyarwanda were transcribed in full by the researcher. The transcriptions were read and compared to audio tape recordings and field notes several times to verify accuracy (Neumann, 2000). A trained, multilingual translator translated the transcriptions into English and the researcher analyzed those transcriptions to identify the main patterns of responses and consistencies and divergences across participants (Jones, 1985). This process involved familiarization with the material on several readings. Common concepts were coded as suggested by Miles and Huberman (1984), producing themes (Ritchie & Spencer, 1994) that were then classified into broader categories. Two weeks after the initial coding, another separate coding was done and the generated themes and categories in the second coding were then compared with the initial coding. This led to further refinements, producing themes and categories that were interpreted for the meaning of the content. The use of code-recode procedure increases the trustworthiness of the results (Mays & Pope, 1995). After the themes and categories had been developed, a further trustworthiness check was made by searching the transcripts for content that could disprove the primary findings, as suggested by Phillips (1987). No disproof was

found. The participants have been coded to protect their anonymity.

3.7 ETHICAL CONSIDERATIONS

Permission to conduct this study was obtained from the Senate Research Grants and Study Leave Committee at the University of the Western Cape (Appendix D), the National Ethics Committee of Rwanda (Appendix E), the Mayor of Musanze District (Appendix F), and the Director of Ruhengeri Hospital (Appendix G).

For the interview participants, different issues were considered. Stroke patients being regarded as a vulnerable group, consent from their guardians was considered. Before conducting the interviews, the aim of the study was explained to both the willing participants and their guardians. An information sheet for the guardians (Appendix H) and the participants (Appendix I) were translated in Kinyarwanda (Appendix J & K respectively), the language used by participants and their guardians, and were given to all guardians and participants for them to read or to be read to them because some were illiterate.

Finally, signed informed written consent was requested from each guardian (Appendix L) and participant (Appendix M) and they were assured of respect, confidentiality and anonymity. All concerned guardians have given their agreement and signed the guardian consent form in Kinyarwanda (Appendix N). Personally, all

selected participants agreed to participate in the audiotape interview, and signed the participant consent form in Kinyarwanda (Appendix O). Participation in the study was voluntary, and the participants were free to withdraw from the study at any time. The participants were told that if anything happened to upset them, counseling services were available for them. During the study, no participant needed counseling. The research assistant signed a confidentiality agreement form (Appendix P).

The final version of the study results will be made available to the staff of the Ruhengeri Hospital, the Ministry of Health and the participants.

3.8 SUMMARY OF THE CHAPTER
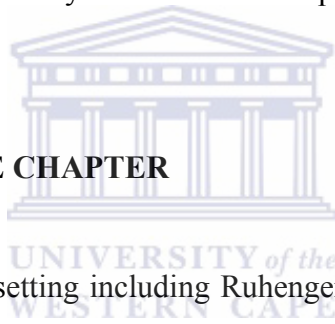
In this chapter, the study setting including Ruhengeri Hospital and Musanze District was described. The researcher highlighted the methods employed in this two-phase study. Phase one consisted of a quantitative retrospective approach by reviewing medical records with a data gathering instrument developed by the researcher to get information regarding the profile of stroke patients. The quantitative results were analyzed using descriptive and inferential statistics. Phase two consisted of a qualitative phenomenological approach using in-depth interviews to explore the challenges experienced by the stroke patients. After the qualitative data collection, a thematic analysis was done. Also included in this chapter are the sampling methods used and the ethical considerations pertaining to the current study.

CHAPTER FOUR: QUANTITATIVE RESULTS

4.0 INTRODUCTION

The results of the quantitative phase of the study which concerns the first four study objectives as stated earlier will be presented in this chapter in five main sections which are the recruitment of participants of the quantitative phase, demographic characteristics, medical characteristics, stroke onset-admission interval and length of hospital stay, and process of physiotherapy. The results will be presented in tables and figures.

4.1 RECRUITMENT OF PARTICIPANTS OF THE QUANTITATIVE PHASE

This section will describe the recruitment of the participants for the quantitative phase of the study, with reference to the inclusion criteria.

A total of 204 stroke patients were admitted at Ruhengeri Hospital between January 1st, 2005 and December 31st, 2008. From those 204, 34 (16.7%) cases were excluded as they had another one or more clinical hypotheses beside stroke: brain tumor in three patients (1.5%), encephalitis in six (3%), hepatic encephalopathy in four (2%), seizures and encephalitis in five (2.5%), hepatic encephalopathy, cardiac failure and brain tumor in seven (3.4%), encephalitis, cardiac failure and brain tumor in nine patients (4.4%).

Out of the remaining 170 cases, marital status was missing in 7 (4.1%) cases, occupation was missing in 15 (8.8%) cases, and the side of body impaired was not indicated in 13 (7.6) cases. A total of 31 cases with missing values were omitted, and then only 139 cases were included for data analysis (n = 139). These included cases are equal to 68% of all 204 identified potential stroke patients. Figure 4.1 summarizes the process of the recruitment of the participants.

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┌─────────────────────────────────────────────┐
│        204 stroke patients identified following      │
│                                               │
│                initial searching              │
└─────────────────────────────────────────────┘
                    │
                    │        ┌──────────────────────────────────────────┐
                    │        │  34 excluded- other clinical hypotheses beside  │
                    ├────────│                                          │
                    │        │                   stroke                 │
                    │        └──────────────────────────────────────────┘
                    ▼
┌─────────────────────────────────────────────┐
│                170 stroke patients            │
│                                               │
│                                               │
└─────────────────────────────────────────────┘
                    │
                    │        ┌──────────────────────────────────────────┐
                    │        │  31 stroke patients excluded- values missing in less  │
                    ├────────│                                          │
                    │        │            than 10% of the cases          │
                    │        └──────────────────────────────────────────┘
                    ▼
┌─────────────────────────────────────────────┐
│          139 participants included for analysis       │
│                                               │
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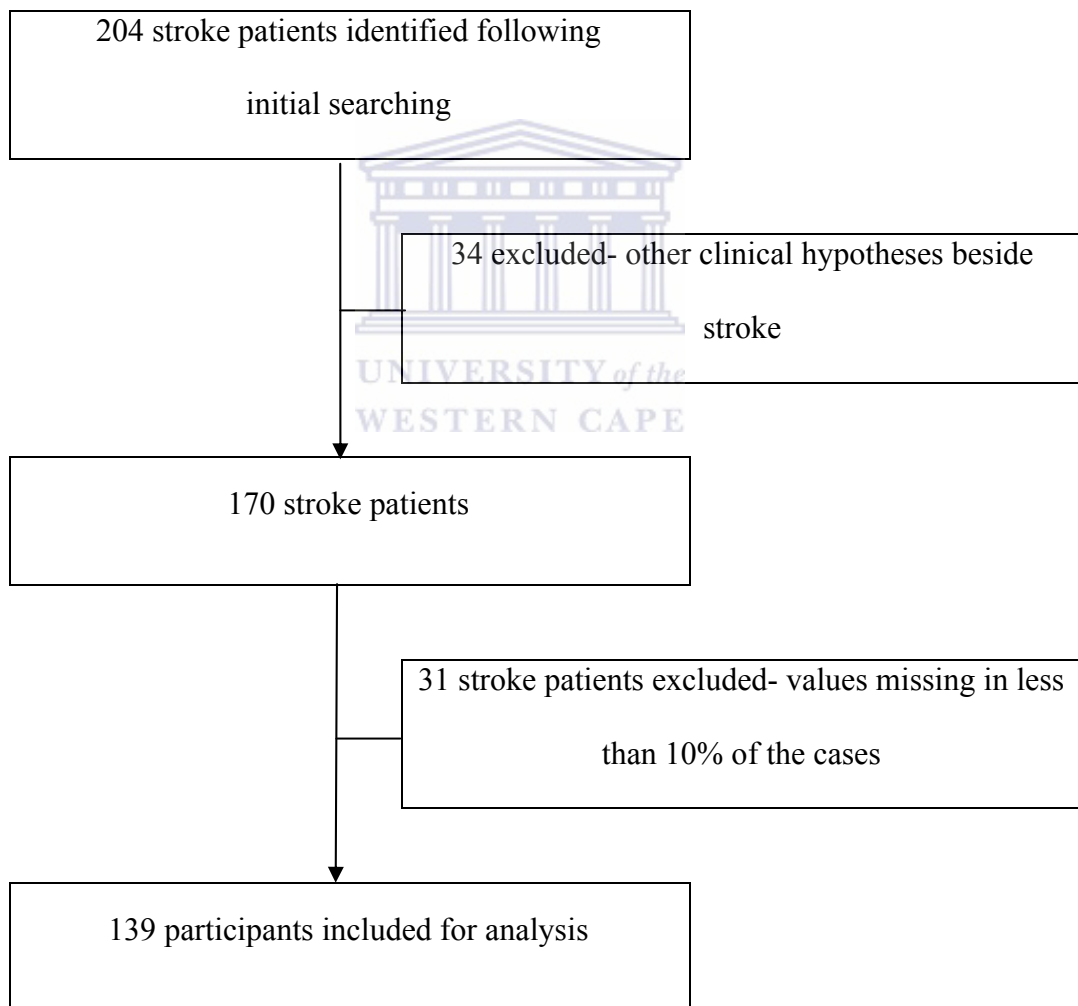
Figure 4.1 Recruitment of participants of the quantitative phase

4.2 DEMOGRAPHIC CHARACTERISTICS OF THE PARTICIPANTS

The following items will be presented in this section of demographic characteristics: age, gender, marital status and occupation.

4.2.1 Age group, gender, marital status and occupation

Table 4.1 presents the age group, gender, marital status and occupation of the participants.

Table 4.1 Age group, gender, marital status and occupation of the participants (n = 139)

Variable	Characteristics	Frequency	%
Age group	15-24	5	3.6
	25-34	11	7.9
	35-44	21	15.1
	45-54	27	19.4
	55-64	25	18.0
	65-74	27	19.4
	75 $\leq$	23	16.5
Gender	Females	74	53.2
	Males	65	46.8
Marital Status	Single	8	5.8
	Married	73	52.5
	Living Together	8	5.8
	Separated	3	2.2
	Divorced	1	0.7
	Widowed	46	33.1
Occupation	Cultivator	87	62.6
	Commerce	10	7.2
	Driver	5	3.6
	Teacher	5	3.6
	Student	5	3.6
	Other occupation	15	10.8
	No occupation	12	8.6
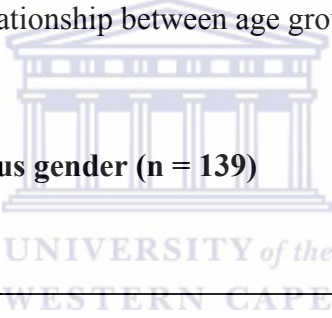
The mean age of the sample was 56.3 years (SD = 17.265) with ages ranging between 17 and 92 years. The majority (64%) of the participants were 64 years old or younger. It was also noticed that 26.6% of all the subjects were younger than 45 years. Only 36% of the subjects were at pensionable age: 65 and above. Seventy-four participants

(53.2%) were females and sixty-five (46.8%) were males. More than half of the participants (52.5%) were married while 46 (33.1%) were widowed. The majority of the participants (62.6%) were cultivators before stroke while 12 (8.6%) had no occupation as an income generating activity. Included in category "other occupation" were 3 carpenters, and the remaining 12 were accountant, artist, cleaner, manager, nurse, painter, pastor, policeman, school director, secretary, soldier and tailor.

4.2.2 Age group versus gender

Table 4.2 illustrates the relationship between age group and gender.

Table 4.2 Age group versus gender (n = 139)

	Gender	Male n (%)	Female n (%)	Total n (%)
Age group	15-24	3 (2.2)	2 (1.4)	5 (3.6)
	25-34	9 (6.5)	2 (1.4)	11 (7.9)
	35-44	12 (8.6)	9 (6.5)	21 (15.1)
	45-54	13 (9.4)	14 (10.1)	27 (19.5)
	55-64	10 (7.2)	15 (10.8)	25 (18.0)
	65-74	12 (8.6)	15 (10.8)	27 (19.4)
	75 $\leq$	6 (4.3)	17 (12.2)	23 (16.5)
	Total	65 (46.8)	74 (53.2)	139 (100)

The male: female ratio was 1.85 (24:13) at ages 15–44, but was 0.67 (41:61) at 45 and older.

At a 0.05 level of significance, the chi-square test of age group versus gender was found to be significant (p = 0.003).

4.2.3 Marital status versus gender

Table 4.3 illustrates the relationship between marital status and gender.

Table 4.3 Marital status versus gender (n = 139)

	Gender	Male n (%)	Female n (%)	Total n (%)
Marital status	Single	4 (2.9)	4 (2.9)	8 (5.8)
	Married	49 (35.3)	24 (17.3)	73 (52.5)
	Living together	6 (4.3)	2 (1.4)	8 (5.8)
	Separated	1 (0.7)	2 (1.4)	3 (2.2)
	Divorced	1 (0.7)	0	1 (1.4)
	Widowed	4 (2.9)	42 (30.2)	46 (33.1)
	Total	65 (46.8)	74 (53.2)	139 (100)

There was a difference between the marital statuses of the females compared to the males. It was notable that 56.8% (42/74) of the females compared to 6.2% (4/65) of males were widowed. There was also a greater number of males who were married 75.4% compared to the females 32.4%. At a 0.05 level of significance, the chi-square test showed that the marital status was significantly associated with gender (p = 0.000).

4.3 MEDICAL CHARACTERISTICS OF THE PARTICIPANTS

This section presents the recorded clinical features and risk factors for stroke. Those characteristics were recorded as documented in medical files (or after interpretation of the documented data related to the clinical features) as explained in section 3.4.1 (B1 and B2) under the development of data gathering instrument.

4.3.1 Clinical features of stroke among the participants (n = 139)

This sub-section presents the recorded clinical features of stroke. The clinical features of stroke type, sensation impairment and muscle tone impairment were missing in 86 (61.9%), 38 (27.3%) and 21 (15.1%) cases, respectively. Thus, those clinical features were not included in data analysis. Table 4.4 presents the documented clinical features of the participants.

Table 4.4 Documented clinical features of the participants (n = 139)

Clinical feature	Frequency	%
Emotional impairment	63	45.3
Cognitive impairment	59	42.4
Vision impairment	59	42.4
Speech impairment	57	41.0
Coma	28	20.1
Side of body impaired		
Right	68	48.9
Left	52	37.4
Both sides	19	13.7
Incontinence		
Bladder	32	23.0
Bladder and bowel	25	18.0
None	82	59.0

Among the 139 participants, clinical features were identified as follows: emotional impairment in 45.3%, cognitive impairment in 42.4%, vision impairment in 42.4%, speech impairment in 41.0%, and coma in 20.1% of the participants. Sixty-eight participants (48.9%) were affected on the right side while fifty-two (37.4%) were affected on the left side. Both sides were affected only in 19 participants (13.7%). Urinary incontinence was reported in 41% while bowel incontinence was reported in 18% of the participants.

4.3.2 Documented risk factors for stroke (n = 139)

4.3.2.1 Frequency of risk factors for stroke among the participants

The table 4.5 reports on the documented risk factors for stroke among the study sample.

Table 4.5 Documented risk factors for stroke among the participants (n = 139)

Risk factor	Frequency	%
Hypertension	84	60.4
Smoking	20	14.4
Diabetes	14	10.1
Cardiac failure	13	9.4
Previous stroke	11	7.9
Transient Ischemic Attack	9	6.5
HIV	1	0.7

Hypertension was reported in 84 patients (60.4%), followed by smoking and diabetes reported in 20 (14.4) and 14 (10.1%) participants, respectively.

4.3.2.2 Number of risk factors per participant

Figure 4.2 illustrates the frequencies and percentages of participants according to the number of the risk factors.
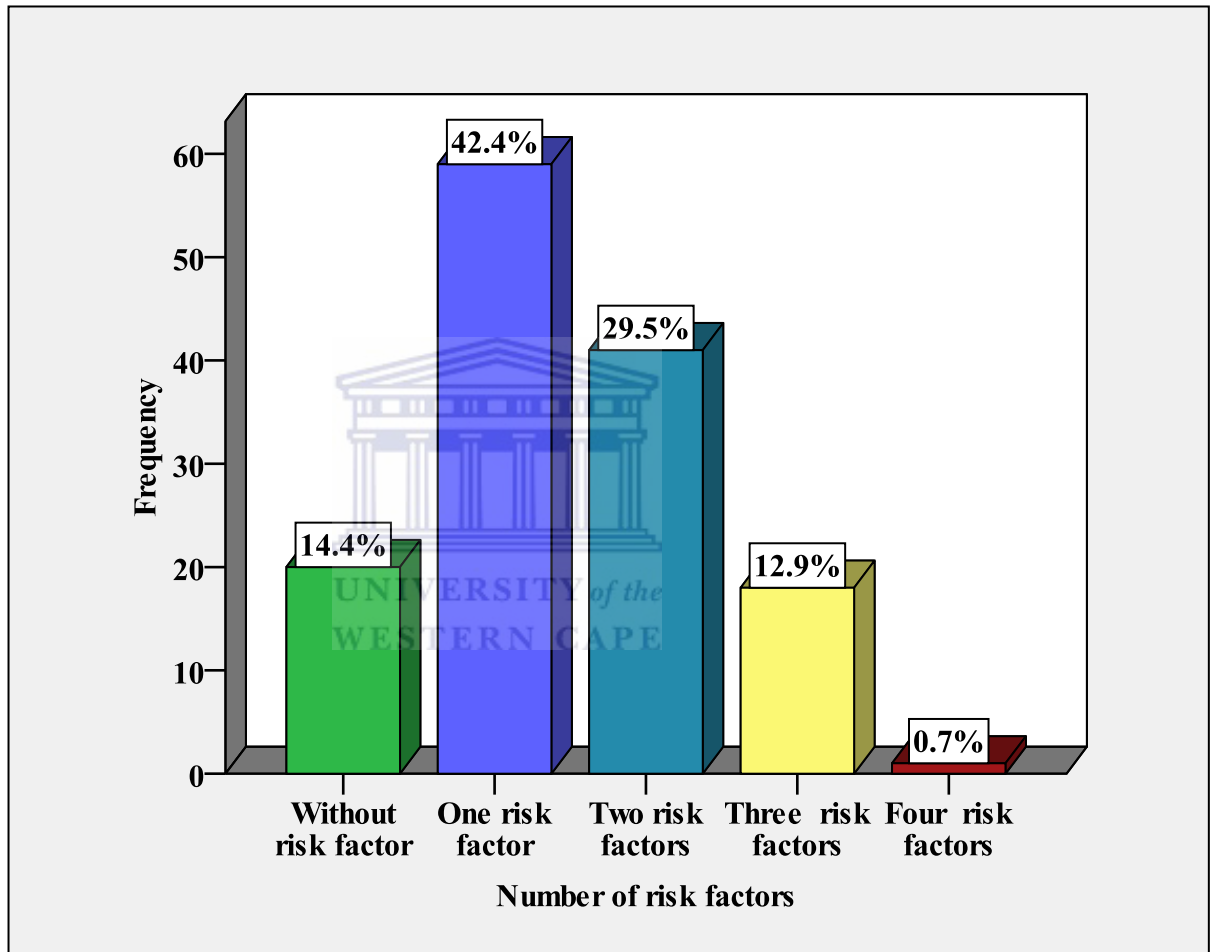
Figure 4.2 Number of risk factors per participant (n = 139)

It was found that 43.1% of the participants were reported to have a combination of at least two risk factors related to stroke.

4.4 STROKE ONSET-ADMISSION INTERVAL AND LENGTH OF HOSPITAL STAY

This section will present the results relating to the stroke onset-admission interval and the length of hospital stay.

4.4.1 Stroke onset-admission interval (n = 139)

The figure 4.3 presents the time between stroke onset and admission.
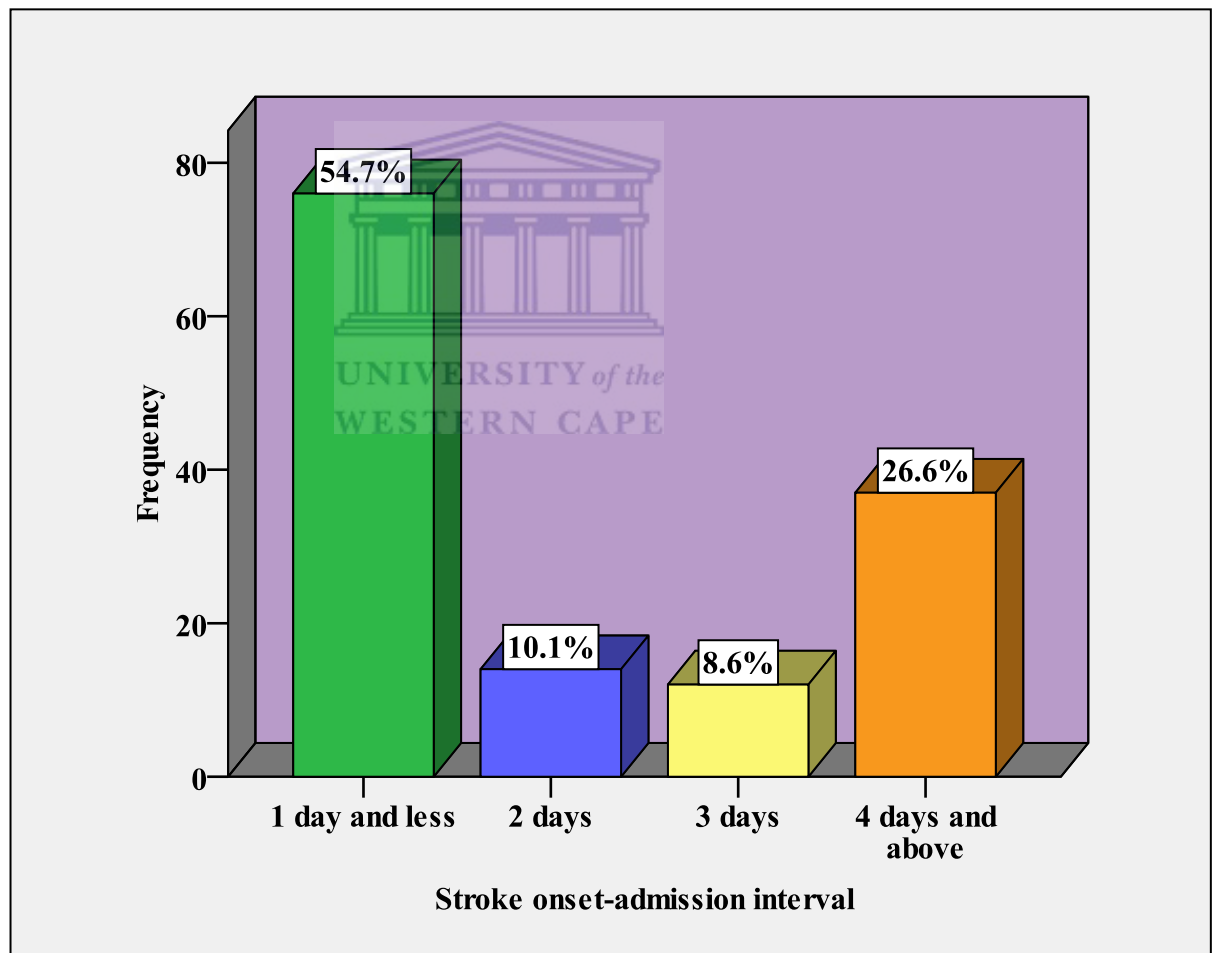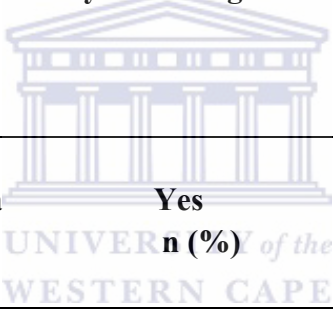
Figure 4.3 Percentages of participants according to stroke onset-admission interval (n = 139)

The participants were admitted to the hospital between the same day of stroke onset and one hundred eighty days after stroke onset (mean = 6.8 days after stroke onset, SD = 18.348). Forty-five percent of the participants were admitted two days or more after getting stroke.

4.4.2 Length of hospital stay (LOS) (n = 139)

Table 4.6 illustrates the LOS in relation to the presence of coma

Table 4.6 Length of hospital stay according to the presence of coma (n = 139)

	Coma	Yes n (%)	No n (%)	Total n (%)
LOS (days)	0 - 4	8 (5.8)	46 (33.1)	54 (38.8)
	5 - 9	13 (9.4)	42 (30.2)	55 (39.7)
	10 - 14	1 (0.7)	6 (4.3)	7 (5.0)
	15 - 19	3 (2.2)	9 (6.5)	12 (8.6)
	20 $\leq$	3 (2.2)	8 (5.8)	11 (7.9)
	Total	28 (20.1)	111 (79.9)	139 (100)

The length of hospital stay of the participants varied between 0 and 172 days (mean = 8.2 days, SD = 10.180 days). The majority of the participants (109/139 = 78.5%) were admitted for 9 days or less. The chi-square test was not significant (p = 0.728), which means that there is no relationship between the occurrence of coma and the length of hospital stay at a 0.05 level of significance.

4.5 PROCESS OF PHYSIOTHERAPY FOR THE PARTICIPANTS

This section will present the results relating to the following items: participants who received physiotherapy, time of commencement of physiotherapy since admission, duration of physiotherapy and the total number of physiotherapy sessions received by the participants.

4.5.1 Participants who received physiotherapy (n = 139)

Figure 4.4 shows the percentage of participants who received physiotherapy during their hospital stay.
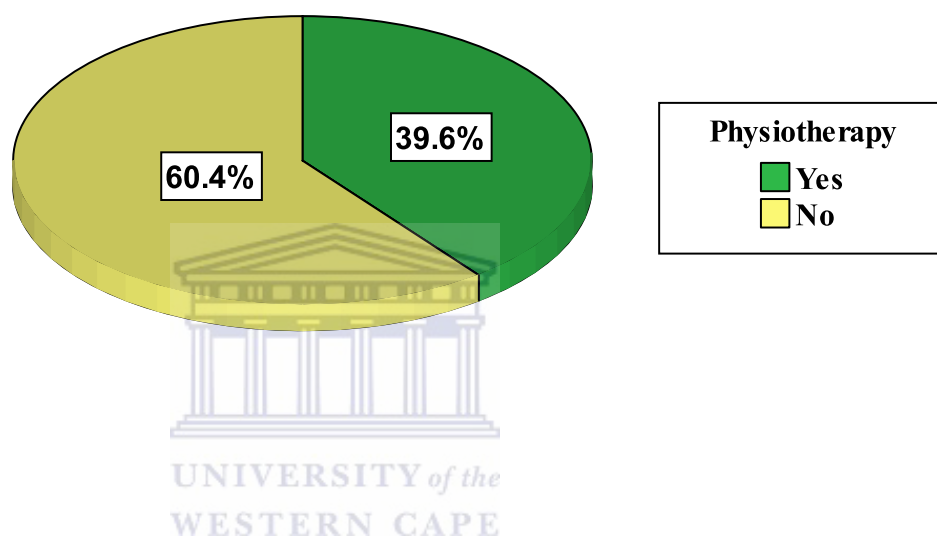
Figure 4.4 Percentage of participants who received physiotherapy (n = 139)

Out of one hundred thirty-nine participants, only fifty-five (39.6%) received physiotherapy. Therefore, only those 55 were considered in data analysis related to physiotherapy with regard to time of commencement of physiotherapy since admission, duration of physiotherapy and total number of physiotherapy sessions (n = 55).

4.5.2. Time of commencement of physiotherapy since admission (n = 55)
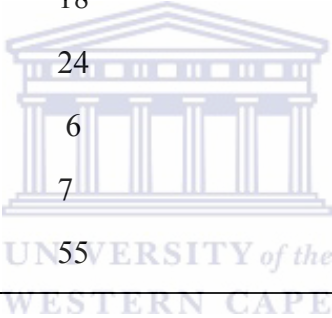
Table 4.7 illustrates the interval between the date of admission and the date of commencement of physiotherapy.

Table 4.7 Interval between the date of admission and the date of commencement of physiotherapy (n = 55)

Time (in days)	Frequency	%
0 - 3	18	32.7
4 - 7	24	43.6
8 - 11	6	10.9
12 $\leq$	7	12.7
Total	55	100.0

Among the participants who had physiotherapy, the majority (67.3%) started to receive the physiotherapy after three days of their admission.

4.5.3. Duration of physiotherapy (n = 55)

Table 4.8 presents the period between the first and the last treatment session.

Table 4.8 Duration of physiotherapy among the participants (n = 55)

Duration (in days)	Frequency	(%)
≤ 4	27	49.0
5 - 9	14	25.5
10 ≤	14	25.5
Total	55	100

The participants received physiotherapy within the period of between one and ninety days, with a mean of 7.6 days (SD = 12.273 days). Out of the fifty-five participants, only twenty-eight (51%) had physiotherapy for more than four days.

4.5.4 Total number of physiotherapy sessions (n = 55)

Table 4.9 illustrates how often the participants used the services of the physiotherapists in relation to the LOS.

Table 4.9 Number of physiotherapy sessions versus the LOS (in days) (n = 55)

	LOS	0 – 4 n (%)	5 – 9 n (%)	10 – 14 n (%)	15 – 19 n (%)	20 ≤ n (%)	Total n (%)
Number	**1-2**	6 (10.9)	13 (23.6)	2 (3.6)	1 (1.8)	3 (5.5)	25(45.5)
of	**3-4**	2 (3.6)	9 (16.4)	0	3 (5.5)	4 (7.3)	18(32.7)
physiotherapy	**5-6**	0	0	1 (1.8)	4 (7.3)	0	5 (9.1)
sessions	**7 ≤**	0	0	2 (3.6)	2 (3.6)	3 (5.5)	7 (12.7)
	Total	8 (14.5)	22 (40)	5 (9.1)	10(18.2)	10 (18.2)	55 (100)

The total number of physiotherapy sessions for a participant varies between one and twenty-four, with a mean of 3.7 sessions (SD = 3.827). The majority of the participants (78.2%) had less than five physiotherapy sessions. A Pearson correlation of the number of physiotherapy sessions versus the LOS found a strong positive correlation (r = 0.763), and this was found to be significant (p = 0.000).

4.5 SUMMARY OF QUANTITATIVE RESULTS

A total of 204 patients were identified as stroke patients admitted at Ruhengeri Hospital between January 1ˢᵗ, 2005 and December 31ˢᵗ, 2008. The final study sample however, only consisted of 139 participants (68%) as 65 patients were excluded due to exclusion criteria or missing and incomplete data. The results revealed that 64% of the study population were 64 years or younger, and the mean age of the sample was 56.3. It was also found that 56.8% (42/74) of the females compared to 6.2% (4/65) of males were widowed. The most common clinical features found in the present study were emotional, cognitive, vision, and speech impairments, and the most prevalent risk factors found in the study were hypertension, smoking and diabetes. The results indicated that only 54.7% of the participants were admitted not later than one day after getting stroke. The majority of the participants (39.7%) fall in the LOS between five and nine days. Only 55/139 participants (39.6%) got physiotherapy, and the majority among them (67.3%) started physiotherapy three days after admission. The mean duration for physiotherapy was found to be 7.6 days with a mean of 3.7 sessions among the study sample.

CHAPTER FIVE: QUANTITATIVE DISCUSSION

5.0 INTRODUCTION

This chapter will discuss the findings of the quantitative phase of the current study with reference to relevant literature. The findings will be discussed under the following main sections: demographic profile, medical profile, stroke onset-admission interval, length of hospital stay, and process of physiotherapy.

5.1 DEMOGRAPHIC PROFILE OF THE PARTICIPANTS

The following items will be discussed in this section of demographic profile: age, gender, marital status and occupation.

The mean age of the sample was found to be 56.3 years. This mean age of the participants is a young age compared to the mean age for acute stroke which is 75 years in developed countries (Graham et al., 2008). However, the present study result was in agreement with Walker et al. (2000) who said that stroke affects younger people in developing countries, possibly 10 to 15 years earlier than in developed countries. The present study results were similar to what was found in a study conducted in Ethiopia (53.2 years) (Zenebe, Alemayehu, & Asmera, 2005) and in Gambia (58 years) (Walker, Rolfe, Kelly, George, & James, 2003). It was astonishing to note that 64% of the participants were 64 years old or younger, meaning below the

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pensionable age and who fall into the economically active group of the population. In developed countries however, only 20% of stroke patients are 64 years old or younger (Johansson et al., 2000). The differences noticed in age distribution in stroke patients between the developed and developing countries are most likely a reflection of the differences in demographic structures between the two groups of countries.

Stroke in the young is a major socioeconomic issue as young patients are more often employed, caring for dependants, and rely on work-related income (Graham et al., 2008). In most instances, stroke in young people results in a long-term burden for the victims, their families and the community (Teasell, McRea, & Finestone, 2000). As younger patients who survive a stroke have a longer time to live with their physical impairments, the cost of stroke in young people exceeds that of stroke in older persons due to the lost productivity and more psychosocial complications (Jacobs, Boden-Albala, Lin, & Sacco, 2002). Therefore, the study findings revealed that the study population comprises a significant amount of patients with special rehabilitation needs such as psychological rehabilitation for the patients and all members of a family system (spouses, children and parents of patients), return to work, and vocational training.

The sample consisted of 53.2% females and 46.8% males. These results are consistent with the results (54% females and 46% males) found in a similar study conducted in South Africa by Rhoda (2002). The fact that the percentage of the female gender is higher than that of the male gender may be explained by the phenomenon as few men

reach old age when compared to women (Beales, 2000). However, some international studies record a slightly higher incidence in males than in females (Walker et al., 2000; Fang et al., 2004; Zenebe et al., 2005).

Zenebe et al. (2005) found that, out of 128 admitted stroke patients in Ethiopia, 60% were men whereas only 40% were women. The men's stroke incidence rates being greater than women's at younger ages (24 men against13 women at ages 15–44), but not at older ages (41 men against 61 women at ages 45 and older) as found in the current study was also reported by the American Heart Association (2009). It revealed that the male: female incidence ratio is 1.25 at ages 55–64; 1.50 for ages 65–74; 1.07 at 75–84 and 0.76 at 85 and older. As older people are significantly more likely to die after a stroke (Connor et al., 2004), the results suggest that at Ruhengeri Hospital, stroke deaths would be higher in males than in females in all age groups up to 44 years, but at 45 and older ages, the mortality would be greater for females.

It was also notable that there was a significant association between gender and marital status: 56.8% of the females compared to 6.2% of males were widowed. This could be linked to results on age indicating that the females in the study were generally older than the males. Considering the fact that females are known to live longer than males (Beales, 2000), this is to be expected. Worell (2001) said that women are much more likely to become widowed than men, since women not only have a longer life expectancy, but also tend to marry men older than themselves. Another contributing factor is that, following divorce or widowhood, women are less likely than men to

remarry (Worell, 2001). This can also be linked to a greater number of males (75.4%) who were married compared to the females (32.4%). It has been suggested that marital status is extremely important in the context of family support. A spouse can be a potential source of practical help and emotional support (Cho, Suh, Kim, Hong, & Kim, 2000). Therefore, the majority of the females with stroke who are widowed as found in the current study are unlikely to get the support.

The findings showed that 62.6% of the participants were cultivators before getting stroke. This is supported by the socio-economic structure of Musanze District, where at least 91% of the population is engaged in agriculture (Musanze District, 2009a). In Rwanda, agriculture is mainly for subsistence and is associated with lower socio-economic status. The term "agriculture" is often used to mean "unemployment". A literature review conducted by Kengne and Anderson (2006) on the epidemiology of stroke in SSA also revealed that stroke patients in SSA have poor socio-economic status: "up to 72% of the patients with stroke have low-income backgrounds, such as labouring jobs" (Kengne & Anderson, 2006, p. 186).

The study findings on occupation suggesting a low socio-economic status are predictors of poor post-stroke outcome (Longo-Mbenza et al., 2000), and a low rate of return to work/occupation post-stroke (Vestling et al. (2003). As suggested by Thomas (2005), the post-stroke disability clearly impacts on an individual's ability to do agriculture. Therefore, the families of stroke patients who were the breadwinners could be left for quite a while with a decrease in their finances or even without any

income. This could place a large financial strain on both the patient and the family. This as a challenge experienced by stroke survivors was explored during the qualitative phase of the study.

5.2 MEDICAL PROFILE OF THE PARTICIPANTS

Data on clinical features and risk factors for stroke was collected to determine the medical profile of the participants. This section will deal with the discussion of the findings about the clinical features and risk factors for stroke among the participants.

5.2.1 Recorded stroke clinical features among the participants

The study findings revealed that emotional, cognitive, vision and speech impairments, urinary and bowel incontinence as well as coma were reported among the participants. These findings on clinical features post-stroke were often consistent with findings from similar studies to identify the profile of stroke patients.

The percentage of the study population reported to present emotional impairment was found to be 45.3%. The present study finding falls in the prevalence range (11–68%) of emotional impairments in Russia as reported by Starchina et al. (2007). Kaplan (2005) indicated that emotional impairment is associated with stroke mortality and poor functional outcome. Furthermore, emotional disorders are sources of further complication and suffering for stroke survivors and their families (Robinson, 2007).

The percentage of the study population with cognitive impairment was found to be 42.4%, and was slightly lower than what (46.2%) was reported by Hayes et al. (2003). While the study conducted by Hayes et al. (2003) was community-based, the present study was limited to stroke patients admitted at the hospital, and this may therefore potentially underestimate the true prevalence of cognitive impairment. It was found that the cognitive impairment has a negative impact on ability to perform ADLs and social roles (Johnston, Sidney, Bernstein, & Gress, 2003). Therefore, a significant proportion of the study population will need more assistance in ADLs and social roles. In order to maximize the functional level post-stroke, rehabilitation strategies for cognitive impairments at the Ruhengeri Hospital should be considered.

The prevalence of vision impairment among the study participants was found to be 42.4%, and it was higher than the prevalence (38%) found by Nys et al. (2007) in Belgium. This difference in vision impairment prevalence could have resulted from the study designs. The study by Nys et al. (2007) was a prospective epidemiological study and used standardized measures, and the current study being retrospective with potential deficiencies in documentation could have slightly exaggerated the figures. The prevalence of vision impairment as found in the study would have a significant negative impact on cognitive ability and functional outcome (Nys et al., 2007).

The percentage of the study population reported to present speech impairment was found to be 41.0%, and was similar to what (40%) was found in Japan by Isagoda and Nakamura (1995), and between 30-60% as reported by Edwards et al. (2006).

The speech impairment as being common, it could enhance higher frequency and severity of cognitive impairment (Nys et al., 2007), emotional impairment (Pohjasvaara et al., 1998), and participation restrictions (Barker et al., 2006). Failure to treat post-stroke speech impairment would therefore not only impede the recovery from stroke but also increase the long-term post-stroke disability.

The results revealed that urinary incontinence was reported in 41% while bowel incontinence was reported in 18% of the participants. This falls in the prevalence ranges found by Barrett (2002) who reported that the rate of urinary incontinence is 40–60%, and the rate of fecal incontinence is reported to be around 20–30% of stroke patients soon after stroke in different care settings. As incontinence seems to be frequent in the participants while it has an impact on survival and functional outcome (Johnston et al., 2003; Kaplan, 2005), such impairment requires attention from the health care professionals.

The present study findings revealed that coma was reported in 20.1 % of the study population. This prevalence of coma was almost similar to 17.2 % found in Japan by Isagoda and Nakamura (1995), and 22.4% found in Brazil by Radanovic (2000). The result on coma occurrence emphasizes that stroke patients at Ruhengeri Hospital need treatment in intensive care unit, and suggests the establishment of a specialized stroke unit.

It was notable from the study that the right side is the most impaired (48.9% against 37.4% and 13.7% for left side and both sides respectively). The results were in agreement with those found in Japan by Isagoda and Nakamura (1995): right side (53.13%), the left side (39.06%) and both sides (7.81). However, Rathore et al. (2002) in US found the left side of the body to be the most affected: 57% for the left, 41% for the right, and 2% for both sides respectively. Jette et al. (2005) found that, out of a sample of 972 stroke patients in US, no significant difference between the two sides: 44% had right-sided hemiplegia, 43% of the patients had left-sided hemiplegia and 13% had bilateral involvement.

The conflicting results could be explained by differences in methodology across studies. For example, while the present study and the study by Isagoda and Nakamura (1995) were both hospital-based and used small sample sizes (n = 139 in the present study and n = 128 in the study by Isagoda & Nakamura), the study by Rathore et al. (2002) was community-based and used a big sample size of 474 participants, and the study by Jette et al. (2005) was rehabilitation setting-based and used a bigger sample size of 972 participants.

It was demonstrated that an individual with left hemiplegia (indicating right hemisphere lesions which is more frequently associated with perceptual impairments) would be expected to have a more negative outcome than an individual experiencing a stroke involving the right side of the body (Barker-Collo & Feigin, 2006). Patients with right hemiplegia (indicating left hemisphere lesions) are those who are most

likely to have speech impairment and would therefore need the services of a speech therapist.

5.2.2 Documented risk factors for stroke among the participants

It was found that 85.6% of the study sample had at least one risk factor, with 43.1% having a combination of two risk factors or more. A study conducted in the Kingdom of Bahrain by Al-Jishi and Mohan (2000) yielded similar results: 89.5% of the study population had one risk factor or more. The risk of stroke increases substantially with the increase in the number of risk factors present. These risk factors are said to interact to increase the probability of a stroke (Tanne, Shlomit, & Goldbourt, 1998). In the present study, as also reported in previous studies (Whisnant, 1997; Radanovic, 2000), hypertension, diabetes, cardiac failure, transient ischemic attacks, previous stroke and smoking were documented either alone or in combination in the majority of the study sample.

The present results correspond with global statistics which report hypertension as being the most prevalent modifiable risk factor for stroke. The result that the hypertension was the most common risk factor in the participants (60.4%) was also found in Bahrain by Al-Jishi and Mohan (2000) (52%) as well as in the Johannesburg Hospital Stroke Register in South Africa by Connor, Modi and Warlow (2006) (69%).

The study revealed that other common risk factors were smoking (14.4%) and diabetes (10.1%), but these frequencies were lower than what were found in the Kingdom of Bahrain by Al-Jishi and Mohan (2000): smoking with 29%, diabetes with 20%; Connor et al. (2006) in South Africa: smoking with 21%, diabetes with 15%. Such differences in frequencies of smoking and diabetes observed between the present study population and other populations are most likely a reflection of the differences in lifestyles among those populations.

Hypertension, diabetes and smoking were found to be associated with stroke mortality (Fang et al., 2004), and they are risk factors related to lifestyles (Kalache & Aboderin, 1995). However, the awareness of the relationship between those factors and stroke is low amongst communities internationally (Hale, Fritz, & Eales, 1998), and this is likely the case nationally. It has been suggested that interventions like primary prevention and control of risk factors can achieve a 2% reduction per annum in overall stroke mortality (Strong et al., 2007). Health promotion programmes that inform communities in Rwanda and in Musanze District in particular, about the risk factors for stroke are therefore suggested.

5.3 STROKE ONSET-ADMISSION INTERVAL

It was notable that the average interval of stroke onset-admission was seven days, and the majority (54.7%) of the participants was admitted not later than 1 day after getting stroke. These results did not support Kengne and Anderson (2006) who said that in SSA, stroke patients often present to the hospital more than a month after onset. The shorter stroke onset-admission interval observed may be explained by the community-based health insurance (CBHI) implemented in all provinces of Rwanda since 2004, and which is meant to assist communities in accessing health care (Ministry of Health, 2004). This program has reduced considerably the number of patients, who stay at home untreated (Diop & Butera, 2005).

However, the stroke onset-admission interval found in the present study is still too long. This is likely to increase the risk of mortality and post-stroke disability. Jacob (2009) recommended that the opportunity to start acute treatment for stroke patients is three hours, and to be evaluated and receive treatment, patients need to get to the hospital within 60 minutes.

5.4 LENGTH OF HOSPITAL STAY

The results revealed that the mean LOS was eight days. This finding is similar to the one found by Williams (2001) in US with the mean LOS equal to nine days, and it is slightly higher to some other reported LOS of four days in Brazil (Radanovic, 2000)

and recently five days in the US (American Heart Association, 2009). The lower LOS reported by Radanovic (2000) and the American Heart Association (2009) concern the treatment in acute facilities where stroke patients, after being medically stable, are discharged earlier from an acute treatment hospital towards a long-term care facility or a rehabilitation setting (Jette et al., 2005). In Rwanda, there are no rehabilitation centres to provide follow-up treatment for stroke patients, and hospitals which provide acute treatment to stroke patients are the same to deliver the post-acute rehabilitation, which should focus to improving function and independence, and preparing the stroke survivor and his or her carers for life after discharge in the context of their previous health, home and family situation, avocational and vocational needs. From hospitals, stroke patients are discharged to their homes. The period of eight days for both acute treatment and rehabilitation before discharge is very short compared for example to the mean length of stay in rehabilitation hospital itself which was found to be 18.7 days in study conducted in US to describe physical therapy provided to patients with stroke in inpatient rehabilitation facilities (Jette et al., 2005).

The observed short LOS may be associated with medical doctors being pressured (militated by a limited capacity of the hospital) towards discharging stroke patients from the hospital environment as early as possible in order to find places for new patients, as highlighted by Pollack and Disler (2002). These authors added that however, that is only possible, or safe, when community resources and infrastructure are adequate, and the timing should depend as much on such resources as the

patient's degree of functional recovery. Successful discharge depends on accurate assessment of the domestic environment, and the establishment of networks to meet critical needs such as personal care, domestic help, home modifications and carer respite.

In the present study, a strong positive correlation between the length of hospital stay and the number of physiotherapy sessions was found. This relationship indicates that the precocity of patients' discharge at Ruhengeri Hospital is a challenge for physiotherapy service delivery as after discharge patients face some difficulties to continue outpatient rehabilitation as it was expressed by the interview participants during the qualitative phase of the study.
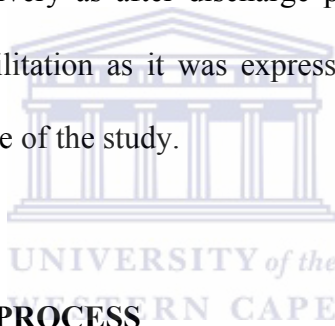
5.5 PHYSIOTHERAPY PROCESS

The physiotherapy process "issues" that were investigated and will be discussed include the participants who received physiotherapy, time of commencement of physiotherapy since admission, duration of physiotherapy and total number of physiotherapy sessions. The results revealed that only 39.6% of the participants received physiotherapy during their hospital stay. This percentage is lower than what (44% to 90%) was found in a similar study conducted by Beech, Ratcliffe, Tilling and Wolfe (1996) analyzing the care provided to stroke patients admitted to 22 hospitals in seven European states. The proportion found in the present study is very low

considering the literature according to which stroke results in a range of disabilities which have been shown to benefit from physiotherapy (Wiles et al., 2004). In developed countries like in Belgium and Switzerland, physiotherapy comprises an important and a relatively large component of the rehabilitation of stroke patients (Jette et al., 2005). The study findings predict a higher prevalence of long-term post-stroke disability even in those with acute mild to moderate disability as the majority of the participants (60.4) do not have a chance to benefit from physiotherapy (Physiotherapy Association of British Columbia, 2007). Those who did not receive physiotherapy are more prone to develop further complications such as joint or muscular problems, and they would need more assistance in ADLs.

The majority (67.3%) of those who had physiotherapy started to receive the physiotherapy three days after their admission. This is in contrast to the recommendations from the Royal College of Physicians (2006), according to which stroke patients should be assessed and start physiotherapy treatment within three days of admission. The mean duration of physiotherapy was 7.6 days. This is consistent with the overall mean LOS which was eight days. Such duration should be supplemented by a long-term follow-up post-discharge as physiotherapy continues to show positive results even beyond six months post stroke (Kwakkel et al., 2004).

While the duration of physiotherapy was 7.6 days, the average number of physiotherapy sessions for the participants was found to be four (4 sessions for 7.6 days), which is the frequency of one session for two days. The result was similar to

three sessions per week found in Ivory Cost by Datié et al. (2006). The result was however very low when compared to the average number of three sessions per two days found in US (Jette et al., 2005). The European Stroke Initiative recommended at least three to four physiotherapy sessions per day for better outcome (Hacke, Kaste, Skyhoj, Orgogozo, & Bogousslavsky, 2000). The frequency at which the study population is treated by the physiotherapists could result in poor outcome as greater frequency of physiotherapy results in better functional outcomes (Teasall & Kalra, 2005).

5.6 SUMMARY OF QUANTITATIVE DISCUSSION

The results revealed a mean age of the study population markedly younger than that reported in studies from developed countries, but such younger age affected by stroke is also found in developing countries. The most prevalent clinical features and risk factors for stroke reported in the present study are well-established for stroke. The results indicated that the stroke-onset admission interval is longer than recommended in the literature, and this could enhance higher case fatality rate and long-term disability. The provision of physiotherapy services for the current study population was found to be lower than suggested by the literature.

CHAPTER SIX: QUALITATIVE RESULTS AND DISCUSSION

6.0 INTRODUCTION

The qualitative phase of the study used in-depth interviews to explore the challenges experienced by stroke patients. This chapter will start with a description of the interview participants, and will follow with the presentation and discussion of categories and themes that emerged. The challenges expressed by the participants can be grouped into three main categories which are activity limitations, participation restrictions and environmental barriers as conceptualized in the ICF (WHO, 2001). In the presentation of the findings, verbatim quotations from interviews will be used to illustrate response themes and categories. For purposes of anonymity and confidentiality, the transcribed quotations of data from the interviews will be cited in the cryptogram **P1** to **P10**. The presentation of categories and themes will be followed immediately by their discussion with reference to relevant literature.

6.1 DESCRIPTION OF THE PARTICIPANTS

In-depth interviews were conducted with 10 participants. Table 6.1 illustrates the characteristics that were considered in purposive selection of the participants: gender, current age, marital status, occupation before getting stroke, chronicity of stroke and ability to walk independently.

Table 6.1 Distribution of the interview participants

Participant no.	Gender	Current age	Marital status	Occupation before stroke	Chronicity of stroke	Independent walking
1	F	24	Single	Student	4 months	No
2	F	45	Widowed	Cultivator	53 months	No
3	F	54	Married	Cultivator	39 months	Yes
4	F	71	Married	Cultivator	14 months	Yes
5	F	79	Widowed	Cultivator	4 months	No
6	M	40	Married	Teacher	3 months	Yes
7	M	53	Separated	Carpenter	7 months	Yes
8	M	57	Married	Tailor	17 months	Yes
9	M	68	Married	Cultivator	22 months	No
10	M	72	Widowed	Cultivator	25 months	Yes

Five participants (50%) were females and other five (50%) were males. The participants were aged between 24 and 79 years (mean age = 56.3years, SD = 16.9 years). Half of the participants (50%) were married while three (30%) were widowed. The chronicity of stroke among the participants lies between 3 and 53 months (mean = 19 months, SD = 16.4 months). Only 60% of the participants were able to walk independently.

Eighty percent of the participants were involved in manual activities before the stroke, and the majority (60%) among them were cultivators before getting stroke. In Rwanda, agriculture is mainly for subsistence and is associated with low socio-economic status. At the time of interviews, five participants lived in Ruhengeri Town and five others in rural area in Musanze District. Among those who lived in town, only one was living in her own house, another was living in the house of his brother, while two participants had left their homes in rural areas, to stay near the hospital for continuing physiotherapy rehabilitation as outpatients. Among these two participants, one was renting a house; another one was living in her son's family in town. The remaining participant who lived in town was staying in a centre for Religious Sisters who accepted to assist her for accommodation and food, and sometimes fees for physiotherapy rehabilitation. Out of 10 participants, only one lived in a house with a toilet inside. Others were living in houses with toilets outside in form of latrine. During the interviews, the participants in general showed an unhappy mood, but they were open to respond to the researcher's questions.

6.2 ACTIVITY LIMITATIONS EXPERIENCED

In the in-depth interviews, when participants were asked to describe the problems they were having since they got stroke, three themes related to activity limitations emerged: limitations in walking, limitations in self care activities, and limitations in domestic life activities.

6.2.1 Limitations in walking

Limitations in walking were described by the majority of the participants interviewed, and varied from total loss of walking to a decrease in independent walking. Participants who were not able to walk expressed the dramatic negative effect of the stroke on walking as reflected in the following quotes:

"Since I became sick in 2004, I have never been able to walk and I always use a wheelchair to go somewhere" (P2).

"… I have a problem of not being able to walk, for me to reach somewhere they (caregivers) *lift me in their arms"* (P5).
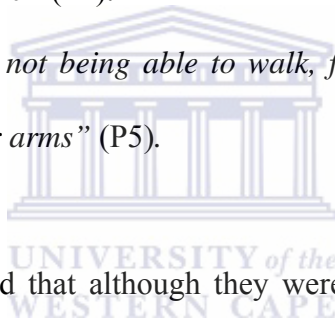
Some participants revealed that although they were able to walk, their capacity to walk independently had been reduced as quoted below:

"… I feel sad that I cannot walk as normal and I am always at home. You see, when I am walking it is like I am walking on one leg and I am pulling this other leg...When I walk out of the house I use a stick, but I can't go beyond that road" (P3).

"… I walk very slowly ... I am no longer able to walk for a long distance. When I am walking even with a stick, I become tired in short time" (P10).

The limitations in walking as expressed by the participants were also reported in similar studies (Clarke et al., 1999; Hendricks et al., 2002; Pearson et al., 2004).

Twenty to twenty-five percent of all stroke survivors are unable to walk without full physical assistance (Hendricks et al., 2002). Participants in a qualitative patient-centred study conducted in UK by Pound et al. (1998) also reported decreased ability to walk independently among their challenges post-stroke. In that study a participant said: "*I missed being able to walk like a soldier, as I seem to have been taught…* (Pound et al., 1998, P. 342) ". The inability to walk among the participants is not surprising given the stroke event which is commonly associated with weakness or paralysis in the legs, or problems with balance. Additionally, some characteristics of the living area of the participants such as mountains, uneven grounds, stones or steps were barriers for those who could walk independently. Such barriers will be highlighted separately in section 6.3.3. Independent walking is often used as an indicator of functional recovery in stroke (Hamzat & Okesola, 2006), and limitations in walking would cause other musculo-skeletal complications as well as further dependence in ADLs and social isolation (van de Port et al., 2006). The study findings therefore suggest the rehabilitation strategies aiming to improve the ability to walk among the study population.

6.2.2 Limitations in self care activities
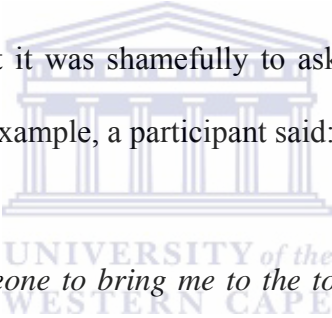
All the participants frequently raised dependence in self care activities such as bathing, eating, going to toilet and dressing. This dependence was reflected by the need of assistance and was a source of feelings of shame. Furthermore, the

participants were psychologically affected by those "issues" around limitations in self care activities. Participants expressed the need for assistance to carry out the self care activities as quoted below:

"… I cannot feed myself without assistance … Oh! So many problems came together; I cannot even bath myself … (P1)*".*

"… Now I cannot dress by myself. It is difficult when it comes to put on the belt or to close the buttons…my wife helps me" (P7).

Some participants felt that it was shamefully to ask somebody to assist them in so basic daily activities. For example, a participant said:

I t is very sad to ask someone to bring me to the toilet. It is very shameful for me" (P1).

Many respondents were uncomfortable with their dependence in self care and did not wish to burden their relatives, friends or volunteers, and this was a source of being psychologically affected in a way that the participants wondered why they did not die instead of living and burdening others. For instance, the participants expressed:

"… I cannot do anything for myself. You see, now it is my daughter in-law who is feeding me, washing me and dressing me. … She is newly married with my son and now rather than working for their new family; she is always with me to assist me …

What they did for me is enough. I wish that I should go back to my home and wait my

death" (some tears came out of the eyes) (P5).

"... I feel like being a burden to the family as I am being assisted in everything ...

Better I should have died already" (P8).

When asked to describe the troublesome effects of the stroke, most of the feelings

that spontaneously emerged in participants' interviews were related to dependence in

self care activities. The interview results were consistent with the results from a

similar study conducted in the UK by Pound et al. (1998), in which the participants

expressed limitations in self care activities including bathing and dressing. Another

qualitative study conducted in the UK and which aimed to investigate stroke

survivors' reports of eating-related experiences six months after stroke revealed that

the majority of the study participants had from slight to moderate eating difficulties

(Perry & McLaren, 2003). The interview results were also consistent with the results

from a quantitative cross-sectional study conducted by Pajalic et al. (2006) in

Sweden, and which showed that out of 89 stroke patients, 25 participants were dependent

in bathing, 24 participants were dependent in eating, and 21 participants were

dependent in dressing.

The fact that the participants were psychologically affected by the dependence in self

care activities was also found in another qualitative study carried out in Australia by

Ch'Ng et al. (2008) employing focus group discussions. The post-stroke

psychological problems are most frequent in younger stroke patients (Ch'Ng et al.,

2008). For younger and single participants, the stroke and resulting disability are perceived as reducing their chances of finding and maintaining an intimate relationship (Ch'Ng et al., 2008). Considering the fact that the majority of the present study population is affected by stroke at young ages, the emotions expressed by the participants are not surprising. In longer term, the dependence in self care activities could lead to emotional challenges including depression, anger, suicidal thoughts and a sense of loss (Ch'Ng et al., 2008).

The present study findings suggest the need of rehabilitation strategies like occupational therapy to help the stroke patients achieving dependence in self care activities, and psychological support services to deal with the psychological problems associated with dependence.
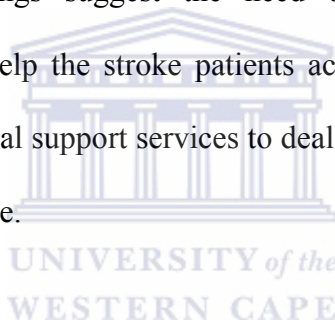
6.2.3 Limitations in domestic life activities
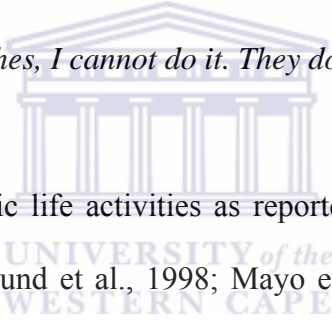
The participants did not only have problems with walking and self care activities, but also displayed problems with domestic life activities such as cooking, washing clothes and cleaning the house. While some participants felt that they were able to do only part of the domestic activities, others expressed that they could not do anything. The need for assistance in domestic life activities was expressed by the participants as illustrated by the following quote:

"… I can cook, but I cannot get water myself and I cannot lift the food from the kitchen. When I am cooking, I call someone to come and help me" (P2).

Some participants revealed that they could not do any part of their domestic activities. For example, a participant said:

" … Oh, I cannot do anything with my hands … when others have gone to work, I try to see if I can clean the house, but it is very hard … I cannot do it (expressed with emotion) (P4)*"!*

" … Even washing my clothes, I cannot do it. They do it for me" (P3).
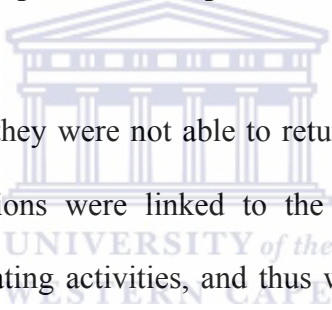
The limitations in domestic life activities as reported by the participants were also found in other studies (Pound et al., 1998; Mayo et al., 2002; Pajalic et al., 2006). Pound et al. (1998) found that a frequent cause of disadvantage to people with stroke was their inability to do housework activities after the stroke. A study conducted in Sweden by Pajalic et al. (2006) revealed that 89 study participants surviving from stroke needed assistance in domestic life activities as follows: 58/89 in washing, 50/89 in cooking and 47/89 in cleaning. The limitations in domestic life activities could further lead to emotional challenges including depression, anger and suicidal thoughts (Ch'Ng et al., 2008). From the participants' expressions, one of the roles of professionals involved in stroke rehabilitation is to improve the ability to do domestic activities.

6.3 PARTICIPATION RESTRICTIONS EXPERIENCED

Participation refers to the ability of the person to manage the role he/she was previously fulfilling (WHO, 2001). As domains of participation restrictions, the participants' expressions were related to three main themes: inability to return to previous occupation, decreased social interactions and inability to participate in religious activities.

6.3.1 Inability to return to previous occupation

Participants reported that they were not able to return to their previous occupations. The participants' expressions were linked to the fact that they were no longer involved in income generating activities, and thus were economically dependent on others. The following quotes illustrate the feelings from the participants highlighting that they could no longer take part in productive activities:

" … I was a cultivator and I used to work in my fields and my children were helping me, and now they are working alone, I am not helping them to cultivate my fields … I cannot do anything … What happened to me is that I cannot do anything" (P5).

''… I am always at home … I am not able to go to cultivate as I used to do before getting this disease …" (P3).

As a consequence of the lack of ability to perform the income generating activities, the participants expressed their concern related to economical dependence as illustrated below:

'' *… You understand, now I cannot get money and I am being fed like a child* (expressed with great emotion)*"* (P3).

"… before I got sick I was a carpenter, but now I cannot do it to get money, and I have to get what I need from my children" (P7).

The inability to return to previous work as a challenge experienced by stroke patients was also found in other various studies (Clarke et al, 1999; Dowswell et al., 2000; Green & King, 2009). For instance, in a qualitative study conducted in Canada by Green and King (2009) exploring patients' perceptions on quality of life 12 months following stroke, the participants reflected that they were experiencing loss in terms of inability to return to normal work-related tasks. The challenge of inability to return to previous occupation could be associated with the inability to walk. According to Vestling et al. (2003), being unable to walk independently after stroke is a barrier to return to work. To go in the fields for cultivating, one must be able to walk and reach there. However, during the interviews, the participants expressed that they had difficulty to move out of their homes. This could be a result not only from the stroke-related impairments, but also from the barriers such as the mountains and uneven pathways made of stones which characterize Musanze District.

Although the inability to return to previous occupation is commonly reported in various studies, in the present study it was more frequently expressed than in a similar study conducted by Vestling et al. (2003). While the other study showed that only 59% of the participants with an average of a one-year period post-stroke were not able to return to their previous occupations, all the present study participants with longer post-stroke period (19 months in average) revealed that they were unable to return to their previous occupations. This difference in returning to previous occupation may be associated with the types of occupations before stroke. Eighty percent of the current study participants compared to only 56% of the participants in the study by Vestling et al. (2003) had manual occupations before stroke. This is most likely the reason why the inability to return to daily occupation is more frequent among the current study participants. According to Saeki et al. (1993), having a manual occupation before stroke is a barrier to return to work. The majority (60%) of the participants was cultivators, and a disability clearly impacts on an individual's ability to do agricultural work (Thomas, 2005).

The consequent economical dependence described by participants is consistent with the findings from the focus group discussions conducted in Ruhengeri and Gisenyi provinces of Rwanda by Thomas (2005). It was revealed that many PWD rely on gifts from friends and family (Thomas, 2005). Considering the young age of the interview participants (the mean age of the sample was 56.3), which is below the pensionable age and falling into the economically active group of the population, the inability to return to previous work or occupation is more than individual. It is a

major socio-economic issue because young patients are more often caring for dependants, and rely on work-related income (Graham et al., 2008). According to Teasell et al. (2000), the inability to return to work frequently leads to emotional and financial hardships for stroke survivors and their families.
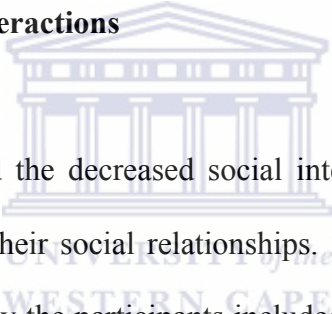
Although stroke survivors may have problems to do agriculture, there are jobs that they can do and they should be given an opportunity to do such jobs. For example, in development activities all over the country (Rwanda), such as cash or food-for-work programmes, stroke survivors can do some jobs such as time-keeping or supervision. Teasell et al. (2000) highlighted that complications including stress in the family, return to work and many future needs in a population affected by stroke at young age should be considered in rehabilitation planning for stroke patients. This would be in agreement with the recommendations by the United Nations (UN) (1993) which states that in both rural and urban areas, PWD must have equal opportunities for productive and gainful employment in the labor market.

While other interview participants cited their inability to return to their previous income generating activities as a disadvantage, the participant who was a student before stroke expressed the challenge of not being able to further pursue studies as quoted below.

"I was in 3rd year of my secondary studies. After I got sick, I stopped studying, and I don't know if I will go back to school again" (P1).

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Not being able to return to school after stroke was also found in a study carried out in Canada by Teasell et al. (2000) investigating social factors and outcomes in 83 stroke rehabilitation patients under the age of 50. It was found that only 20.3% of patients studying at the time of their stroke were able to return to school within three months of their discharge to home (Teasell et al., 2000). With some functional improvement, the student with stroke may be able to return to school. However, the school should be ready to accommodate such a student with disability.

6.3.2 Decreased social interactions

The participants described the decreased social interactions when probed to tell if there was any change in their social relationships. Sub-themes related to decreased social interactions as felt by the participants included not being able to get out of the house, and being separated from the family and neighbors by leaving their homes. For example, a participant who was not able to walk remarked:

" … I cannot reach where others are. I visit nobody. You understand it's very hard. I just sit in the house till somebody comes to see me" (P9).

Also, some participants experienced the decreased social contact because they changed residences after having stroke, and this resulted in changes in their usual social relationships as described by the participants:

" … As of now, I have moved from home to stay near the hospital to continue physiotherapy, it is difficult for my neighbors at home to come from very far to visit me" (P8).

"My children come sometimes from home to visit me where I stay … but they do not come always. It is very far; it is about one hour driving" (P5).

The decreased social interactions reported by the participants were also noted in many previous studies (Pound et al., 1998; Burton, 2000; Ch'Ng et al., 2008; Salter et al., 2008). For example, in a qualitative meta-synthesis of studies from Australia, Canada, Sweden, UK and US conducted by Salter et al. (2008) examining the experience of living with stroke, a decrease in social interactions was found. The majority of participants across studies appeared to experience feelings of increasing social isolation, social withdrawal and/or altered relationships with both families and friends (Salter et al., 2008). Participants reported that the decrease in social interactions was an inevitable consequence of no longer being able to go out and take part in previous activities, but also some felt they were being rarely visited because they had left their homes and were living very far from their homes. A study conducted in the UK by Dowswell et al. (2000) also reported that some participants had moved house since the stroke, and consequently they experienced a change of neighborhood having an effect on social networks.

Relationships are perceived to be important, not only for comfort and support, but also for maintaining a sense of continuity (Salter et al., 2008). The decreased social

interactions experienced by the participants would have a negative impact on social support networks (Chau et al., 2007), while these networks have a positive influence on a stroke patient's functional and psychosocial recovery (Chau et al., 2007; Salter et al., 2008). According to the National Guideline on Stroke and Transient Ischaemic Attack Management (2001), feelings of decreased social interactions should not be overlooked and should be attended to at outreach rehabilitation services such as the community health centres, day programmes or home visits by members of the stroke rehabilitation team.

6.3.3 Inability to participate in religious activities

Participants expressed their concern of not being able to participate in religious activities, and the issues related to this as remarked by the participants were inability to walk and the pain associated with walking for those who were able to walk, as illustrated below:

" … I am a Pentecost, but after getting sick I have never been to church to pray God because I cannot walk" (P5).

" … I go to church less than usual because I cannot reach there by myself … I have lost my Christianity! Since I got sick, I went to church few times. It is only possible when my husband is there and brings me to church by car" (P2).

" … Normally I am an Adventist, but currently I do not go to pray … When I walk for

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about two hours I feel much pain requiring stopping and resting … It is very sad that

I cannot go to pray" (P6).

Loss of participation in religious activities was also reported in a study conducted in the UK by Dowswell et al. (2000). In this study, a participant indicated: "*Oh it's very hard. I cannot get to church...* (Dowswell et al., 2000, p. 511)". While the participants expressed their difficulties to attend religious activities in churches, it was reported that prayer, religious beliefs and involvement with church communities provide some stroke patients with a sense of perspective about their disease as well as providing social support (Ch'Ng et al., 2008). The current study population which is psychologically affected by the stroke itself, the dependence in ADLs, and the social isolation may therefore develop more anxiety and depression which could be prevented by having an opportunity to take part in church activities (Mueller, Plevak, & Rummans, 2001). Therefore, the study findings suggest that there is need for specific rehabilitation programmes to address the limiting factors in order to enhance the participation in various social activities by the stroke survivors.

6.4 ENVIRONMENTAL BARRIERS EXPERIENCED

Environmental barriers are environmental factors that inhibit a person's ability to participate in activities or spend more time to do so (WHO, 2001). The feelings from the participants that emerged during the interviews as environmental barriers can be classified into three themes which are social, attitudinal and physical barriers. The sub-themes emphasizing each theme will be highlighted.

6.4.1 Social barriers

The sub-themes related to social barriers as described by the participants were lack of social support, and inaccessible physiotherapy services.

6.4.1.1 Lack of social support
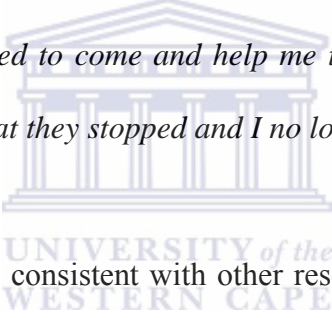
There were mixed feelings with regard to social support. When asked if the society was supporting them, the participants described family members and other people to be supportive, but some participants reported lack of support from the relatives since having stroke, and others felt that the support was decreasing as time progressed. For example, a participant said that she was not supported by the family members:

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"All my relatives have turned away from me…they do not care for me. I look after myself because I don't have anyone to take care of me" (P2).

Some participants emphasized in common that as the period of the disease lengthened, social support became less frequent as illustrated by the following quotes:

" … at the beginning, people were highly willing to help me, I was being helped by relatives and volunteers, but as it took a long time, they became tired, and often they no longer come to visit me" (P4).

"… sometimes, people used to come and help me to go to church to pray and this was for two years. After that they stopped and I no longer go to church" (P2).

The interview findings are consistent with other research findings where the lack of social support was a frequent experience of stroke patients (Ch'Ng et al., 2008; Lynch et al., 2008). For example, Lynch et al. (2008), in their qualitative study in US on dimensions of quality of life that are important to patients after stroke, found that lack of social support was one of the experiences of the stroke patients. Some participants expressed that the support became less and less as the period of their disease became longer. It was found that the mean of chronicity of stroke was 19 months among the interview participants. This period is very long when a patient is supported by others, especially when these are volunteers and not relatives. They may become tired and stop their support. The findings supported Dorsey and Vaca (1998) who noted that as time passes, social activities and contacts with stroke survivors begin to diminish.

Literature highlights the important role of social support in stroke rehabilitation (Salter et al., 2008). Results from quantitative studies indicated that the social support has a positive influence on a stroke patient's functional and psychosocial recovery (Chau et al., 2007; Salter et al., 2008). As the current study population is composed of vulnerable individuals with low socio-economic status, some being widowed and old, in addition to the acquired post-stroke disability, the lack of social support would be a barrier to the emotional, informational, and instrumental or appraisal support that they need. Consequently, the lack of social support would have a negative impact on their functional and psychological recovery, and social reintegration post-stroke. Therefore, measures to encourage social support for people with stroke in Musanze District are suggested.
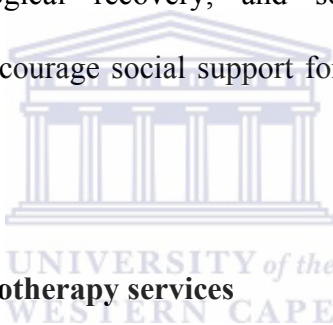
6.4.1.2 Inaccessible physiotherapy services

Many participants raised their problem to continue physiotherapy rehabilitation at the hospital, as this was not accessible. This was expressed with regard to the limitations in walking and the high cost of transport. The following quotes illustrate the problem:

"When I was discharged from the hospital, the doctor told me to continue physiotherapy for three times a week. Oh, it is hard for me! I cannot walk...my caregiver and I need transport to reach there, and it is very expensive" (P5).

" … the hospital is very far, and the transport to go there for physiotherapy is very expensive … To go to the hospital every single day is RWF (Rwandan Francs) *three*

thousand, it means RWF nine thousand every week (= US Dollars 17 by the interview period)*, the money is finished. I decided to get a private home physiotherapy treatment as it becomes cheaper, but sometimes the physiotherapist does not come"* (P7).

" *… Physiotherapy treatment is very important but I have problems to attend the prescribed physiotherapy services at the hospital … There is no problem to pay treatment services because of community health insurance, but the problem is about transport to reach the hospital. I have decided to leave my home and come here in town near the hospital … I can walk slowly and arrive at the hospital, but sometimes I have to use private transport and it is very expensive* (P8).

The participants' expressions regarding the lack of transport to access physiotherapy rehabilitation were consistent with the findings from the in-depth interviews in New Zealand used to explore the perceptions of individuals with stroke towards outpatient physiotherapy in the hospital, and home-based settings (Hale, Bennett, Bentley, Crawshaw, & Davis, 2003). Similarly, the participants expressed that it was difficult for them to attend outpatient physiotherapy in the hospital due to lack of transport (Hale et al., 2003). The situation of the current study participants was more difficult as these were poor and were no longer involved in income generating activities and they could not find themselves money for transport.

In other countries like Turkey, Thailand, Brazil, United States and Italy, stroke patients, after the clinical stability of stroke is achieved in acute treatment hospital,

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are ushered into rehabilitation settings (Savas et al., 2007). In Rwanda, there are no such rehabilitation settings for stroke patients, and these are discharged to their homes. The UN, in its Standard Rules on the Equalization of Opportunities for Persons with Disabilities, recommends that states should ensure that all rehabilitation services are available in the local community where the PWDs live (UN, 1993). However, in Musanze District, there is no provision of home-based or outreach or community-based rehabilitation programmes, and PWDs can only get the rehabilitation services at the hospital as outpatients.

Broadly, PWDs in Rwanda share the same difficulties that other Rwandans without disabilities face in accessing health care, but there are some differential factors. For example, most of the current study participants need assistance to reach health facilities. According to the Ministry of Health (2002), only 5% of Rwandan PWDs are able to access the services they need. The inaccessibility of physiotherapy services as experienced by the study participants is likely to interfere with the functional outcomes, social participation and social re-integration, and would increase other medical complications (Savas et al., 2007). Therefore, the study results emphasize the need of provision of transport facilities, home-based or community-based rehabilitation programmes for stroke patients.
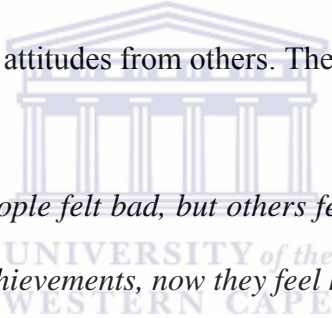
6.4.2 Attitudinal barriers

The perceived attitudinal barriers were related to people's negative attitudes, although not frequent. These attitudes varied from people who said that the stroke patients were being punished by God, and those who felt happy after their rivals in achievements got stroke.

P2 reported: *"People are saying that God has punished me"*.

P3 also perceived negative attitudes from others. The participant said:

"When I got sick, some people felt bad, but others felt very happy, for example those who were jealous of my achievements, now they feel happy".
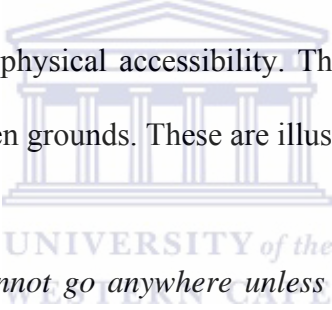
It has been hypothesized that stroke is a stigmatizing condition (Pound et al., 1998), and this has been supported by the study findings as the participants explicitly drew attention to the negative attitudes although not frequent. The negative attitudes perceived by the participants were similar to qualitative findings in a study conducted by Hare et al. (2006) in the UK. According to Thomas (2005), PWDs in Rwanda face negative attitudes, and these are particularly strong towards those with severe disabilities. The negative attitudes as perceived by the participants could result in social isolation for people with stroke, and these may start themselves to avoid deliberately meeting other people.

6.4.3 Physical barriers

There were frequent expressions from the participants with regard to physical barriers. The sub-themes which emerged from the interviews as related to physical barriers included inaccessible pathways and toilets.

6.4.3.1 Inaccessible pathways

When probed about factors that were obstacles in their daily life, participants also mentioned problems with physical accessibility. The barriers which were described are stones, stairs and uneven grounds. These are illustrated by the following quotes:

" … *I stay at home; I cannot go anywhere unless I have someone to assist me … When I am in a wheelchair I cannot push it myself because of stones and stairs within the ways I use*" (P2).

 "*Some ways are not good for me to walk, so sometimes I have to look for other ways which are practical for me. For example, uneven ways make my walking very difficult. So I must take a long way in spite of using a short one which is not practical to use for me*" (P8).

The participants' expressions were in agreement with the reports from a study conducted in Canada by Reid (2004b). In this study, it was found that the outside of the home poses barriers to occupational performance for many individuals with stroke, with key issues including uneven ground and stair access (Reid, 2004b). Also, Udesky (2009) highlighted that for many people who have had a stroke, simply walking again can be extremely difficult, and if there are steps to climb or narrow doorways to pass through, it may seem totally impossible. The present study findings suggest that the physiotherapists should visit the stroke patients' homes to check for potential hazards like stairs and indicate changes to make getting around the houses easy and safe. Given the fact that the ways in the Musanze District are made of stones, and that the Musanze District and the Government of Rwanda are not maybe ready (due to financial reasons) to build better accessible ways or roads, efforts should be put in re-education aiming the walking performance in the patient's community. However, transport facilities to overcome the physical barriers, and to assist the people with stroke to get out the house and take part in social activities are also suggested.

6.4.3.2 Inaccessible toilets

Some participants indicated that they had a problem with the use of toilets, as these were not accessible. This was related to the physical construction of the toilets, and participants revealed the coping strategies they developed.

" … It is hard for me to go to the toilet. The toilet we use here demands squatting and I cannot. … I use a chair" (P8).

" … I cannot really be able to tell you what problems came with this disease. I am struggling to live … I have difficult to go to toilet … There at Kigali (the capital of Rwanda with better accessible physical environment) *where I have been before, there are modern toilets I could use easily, here I have to use a tablet"* (P7).

The challenge related to the accessibility of the toilets was also mentioned by Stein (2004) who said that after a stroke, some people have difficulty rising from a standard height toilet owing to weakness. The Australian Human Rights Commission (2008) reported a woman who had a stroke and who was complaining that there was no accessible toilet at a local arts theatre. The participants' expressions on inaccessible toilets could be expected as most of them live in houses with toilets outside, in form of latrine.

The inaccessible toilets as felt by the participants is a factor for more dependence in self care activities with patients being more psychologically affected owing to their status of dependence. Given the physical construction of the toilets in many rural areas like in Musanze District which is not accessible to people with stroke, and given the fact that the majority of the families are not able to get the modern accessible toilets, in rehabilitation of stroke patients emphasis should be to minimize the dependence for using the available toilets, maybe in encouraging and improving the coping strategies as revealed by the participants.

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6.5 SUMMARY OF QUALITATIVE RESULTS AND DISCUSSION

The qualitative results revealed that the participants perceived the activity limitations including difficulty in walking, self care activities such as bathing, toileting and dressing as well as domestic life activities such as cooking, washing and cleaning. Challenges related to participation restrictions were also experienced and were mostly the inability to return to previous occupation and a decrease in social interactions. These findings were similar to those reported in other various qualitative and quantitative studies. It was found that there were different environmental barriers interfering with ADLs and social integration of the study population. Those barriers included social, attitudinal and physical aspects: lack of social support, inaccessible physiotherapy services and lack of transport, negative attitudes and inaccessible pathways and toilets were described by the participants, as also found in similar studies.

CHAPTER SEVEN: SUMMARY, LIMITATIONS, CONCLUSION, SIGNIFICANCE OF THE STUDY AND RECOMMENDATIONS

7.0 INTRODUCTION

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

7.1 SUMMARY OF THE STUDY
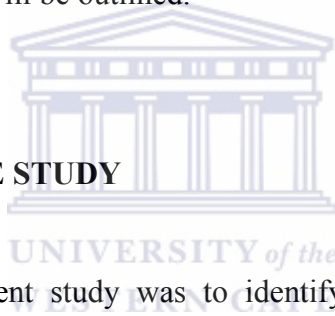
The purpose of the current study was to identify the profile of and challenges experienced by stroke patients admitted at Ruhengeri Hospital in Rwanda from January 1st, 2005 up to December 31st, 2008. Using a quantitative retrospective method with a data gathering instrument, the study specifically investigated the demographic characteristics, medical characteristics, the stroke onset-admission interval and the length of hospital stay as well as the process of physiotherapy for the stroke patients. Employing the in-depth interviews, the study also explored the challenges experienced by stroke patients.

The quantitative results indicated that the mean age of the study population was 56.3, and this age is markedly younger than that reported in other studies from developed countries, but is similar as reported in developing countries. It was also found that 56.8% (42/74) of the females compared to 6.2% (4/65) of males were widowed. The majority of the study population (62.6%) was cultivators before stroke. As well-established in literature, the most prevalent clinical features found in the present study were emotional, cognitive, vision and speech impairments while the most prevalent risk factor for stroke was hypertension. The results indicated that the mean stroke-onset admission interval was 6.8 days and this is longer than recommended in the literature. The mean LOS was found to be eight days, and this is too short for both acute treatment and rehabilitation. The provision of physiotherapy services for the current study population was found to be lower than suggested by the literature.

The qualitative results revealed the activity limitations perceived by the participants including difficulty in mobility (walking), self care activities (bathing, toileting, dressing) as well as in domestic life activities (cooking, washing and cleaning). Other perceived challenges were related to participation restrictions such as the inability to return to previous occupation and a decrease in social interactions. These findings are also reported in other studies. Additionally, the participants in the present study reported the environmental barriers comprising lack of social support, lack of transport to access the physiotherapy services, negative attitudes, inaccessible pathways and toilets as also found in similar studies.

7.2 LIMITATIONS OF THE STUDY

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

For the quantitative phase:

➢ It is of value to consider that the diagnosis, as an inclusion criterion, was confirmed only by the clinician medical doctor and not by radiographic means also.

➢ Data were obtained from a records review and there were many missing data.

➢ Finally, the missing data were managed by case deletion. The limitation with this method is that it reduces the sample size (Worster & Haines, 2004).
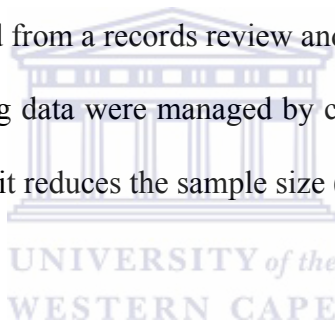
For the qualitative phase:

➢ Individuals with communication or cognition problems were excluded from the interview sample. Therefore, the qualitative sample may only represent a group of individuals with no significant communication or cognition problems post-stroke while the excluded group might have different experiences.

➢ Established guidelines for ensuring methodological and interpretive rigor in qualitative research have been followed, but there is an element of interpretation inherent in qualitative research.

➢ It is also important to note that although individuals who share the experiences in question may best assess the credibility of interpretations (Dingwall, Murphy, Watson, Greatbatch, & Parker, 1998), the researcher was unable to conduct a member check of the analysis as presented.

In the interim, the present study provides the data that can inform public health strategies directed at assessing and reducing stroke severity and stroke events.

7.3 CONCLUSION

The aim of this descriptive study in identifying the profile of and challenges experienced by stroke patients admitted at Ruhengeri Hospital in Rwanda was successfully achieved. In the current study setting, stroke affects young people and most of these people do agriculture. The modifiable risk factors present in the current study population are concerning as they reveal that the lifestyles of the community could lead to a variety of chronic diseases. However, the rehabilitation process of stroke at the Ruhengeri Hospital is a challenge. The study findings demonstrated that after the discharge from the hospital, the stroke-related activity limitations, combined with various environmental barriers, impede heavily the functional and social activities among the stroke survivors.

7.4 SIGNIFICANCE OF THE STUDY

The findings of this study are important for clinicians, researchers and policy makers. Clinically, this study provides medical doctors, physiotherapists and other health professionals with information about demographic status, medical status, stroke onset-admission interval, length of hospital stay, process of physiotherapy, and the challenges experienced by stroke patients. This information could be used by these health care professionals to develop appropriate prevention and rehabilitation strategies for this specific group of patients, not only during the hospital admission, but also after discharge. Such a study at Ruhengeri Hospital provides reliable data for referencing, especially by researchers and policy makers. Subsequently, it is a contribution to the knowledge about stroke in Rwanda.
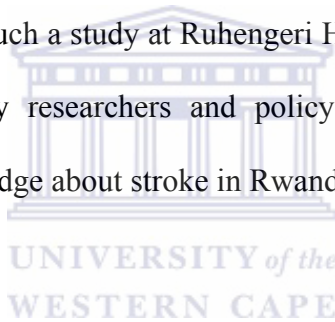
7.5 RECOMMENDATIONS

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

1. Health Policy Makers should develop Health Promotion Programmes to be implemented in public settings such as hospitals, churches, markets and communities, in order to increase awareness and prevention of the risk factors for stroke. These programmes should target both the young and old people in the community.

2. The stroke onset-admission interval is too long. Therefore, community health workers and professionals at health centers should ensure that the stroke sufferers are referred at hospital immediately after the stroke onset.

3. An interdisciplinary team approach should be implemented by the Ministry of Health. Therefore, the need for the training and employment of occupational and speech therapists is strongly urged. These staff members might not only be needed for stroke survivors but for clients with speech or swallowing and independent function problems resulting from other conditions.

4. Health professionals such as physicians and physiotherapists should make efforts in designing early and intensive physiotherapy rehabilitation for stroke patients.
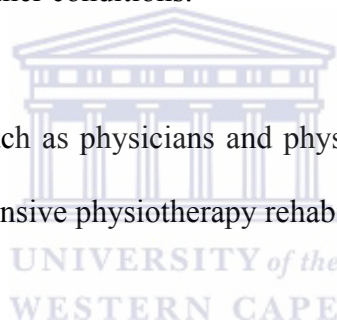
5. Formalized discharge planning procedure for stroke patients should be developed by the clinicians. Accurate assessment of the domestic environment and the establishment of networks to meet critical needs such as personal care, domestic help and home modifications should be considered before discharge.

6. Primary care providers, particularly physiotherapists, should develop and implement home and community-based rehabilitation interventions that target stroke survivors. It is also recommended that family and community members play an important role in the re-integration of PWDs, especially stroke survivors.

7. Measures to enable a barrier-free physical environment in homes and community remain a top priority for service provision that should aim to provide opportunities for stroke survivors to resume or to maximize their social life.

8. Complete record keeping is essential for planning of health care services. It is important that the staff at the Ruhengeri Hospital keep correct, complete records relating to all aspects of the assessment and treatment as the records from the hospitalization and physiotherapy departments were found to be poor.

9. Future prospective epidemiological studies that should consider evaluation of stroke clinical features with the use of standardized measures to better evaluate the full clinical scope of stroke events are recommended to researchers interested in stroke profile.

10. Authorities responsible for development programmes should pay special attention for the involvement of the stroke survivors in income generating activities in place as it is difficult for them to return to their previous manual occupations such as agriculture.
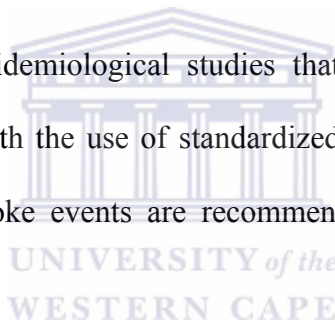
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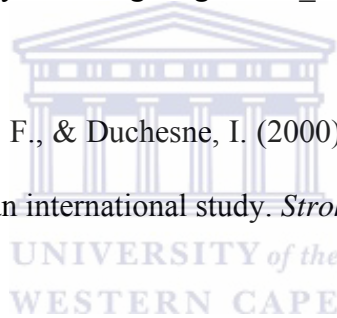
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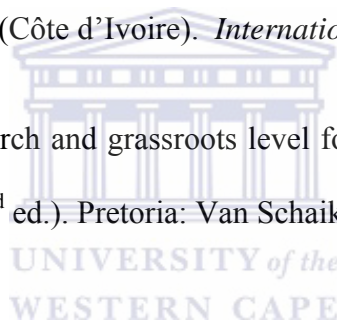
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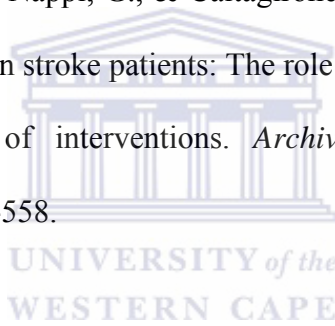
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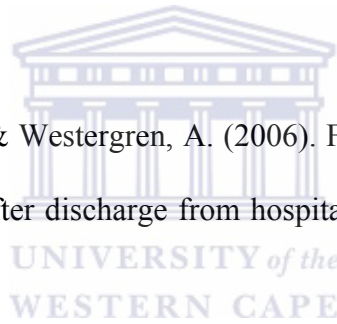
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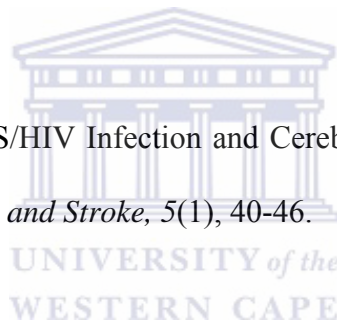
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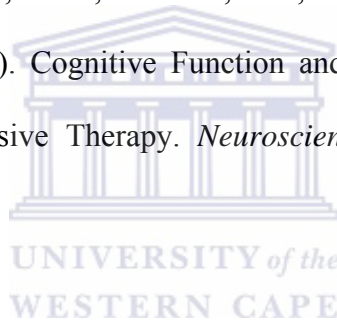
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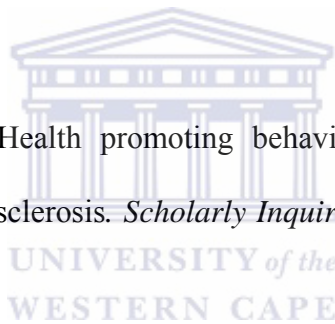
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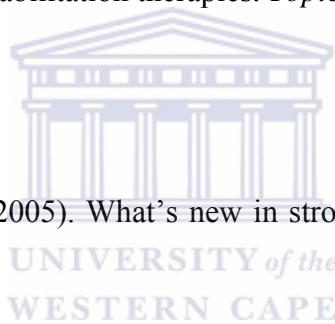
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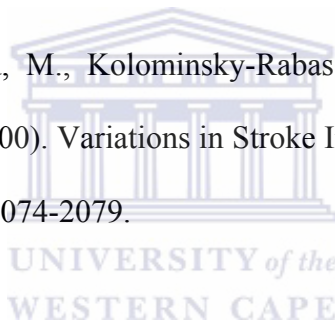
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APPENDICES

APPENDIX A

DATA GATHERING INSTRUMENT FOR MEDICAL RECORDS REVIEW

A. DEMOGRAPHIC DATA

I.1. Age:……………..

I.2. Gender: ☐ 1. Male

☐ 2. Female

I.3. Marital status: ☐ 1. Single

☐ 2. Married

☐ 3. Living Together

☐ 4. Sepatated

☐ 5. Divorced

☐ 6. Widowed

☐ 99. Missing

I.4. Occupation:……………………………………….or ☐ "99": Missing

B. MEDICAL DATA

B.1 Clinical features:

I.5. Type of the present stroke: ☐ 1. Ischemic

☐ 2. Hemorrhagic

☐ 3. Association of both types

☐ 99. Missing

I.6. Occurrence of coma: ☐ 1. Yes

☐ 2. No.

☐ 99. Missing

I.7. Cognitive impairment: ☐ 1. Yes

☐ 2. No

☐ 99. Missing

I.8. Vision impairment: ☐ 1. Yes

☐ 2. No

☐ 99. Missing

I.9. Speech impairment: ☐ 1. Yes

☐ 2. No

☐ 99. Missing

I.10. Emotional impairment: ☐ 1. Yes

☐ 2. No

☐ 99. Missing

I.11. Muscle tone impairment: ☐ 1. Flaccidity

☐ 2. Spasticity

☐ 3. None (Normal)

☐ 99. Missing

I.12. Side of body impaired: ☐ 1. Left side

☐ 2. Right side

☐ 3. Both sides

☐ 99. Missing

2
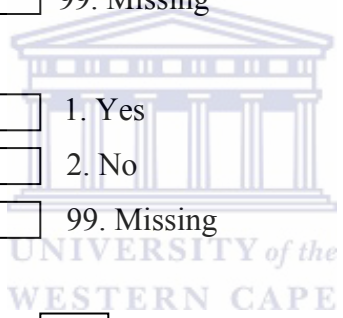
I.13. Incontinence: ☐ 1. Bladder incontinence

☐ 2. Bowel incontinence

☐ 3. Both bladder and bowel incontinence

☐ 4. None

☐ 99. Missing

I.14. Sensation impairment: ☐ 1. Yes

☐ 2. No

☐ 99. Missing

I.15 (B.2) Risk factors related to stroke: ☐ 1. Hypertension

☐ 2. Diabetes

☐ 3. Cardiac failure

☐ 4. Atrial fibrillation

☐ 5. Transient Ischemic Attack

☐ 6. Previous stroke

☐ 7. Smoking

☐ 8. HIV

☐ 9. None

C. REHABILITATION DATA

I.16. Stroke onset-admission interval (in days): ………….. or ☐ "99": Missing

I.17. Length of hospital stay (in days): ……………..

I.18. Has the patient received physiotherapy after admission? ☐ 1. Yes

☐ 2. No

I.19. Time of commencement of physiotherapy since admission (in days): ………..or ☐
   "88": Not applicable

I.20. Duration of physiotherapy (in days): ………..or ☐ "88": Not applicable

I.21. Total number of physiotherapy sessions: …………or ☐ "88": Not applicable
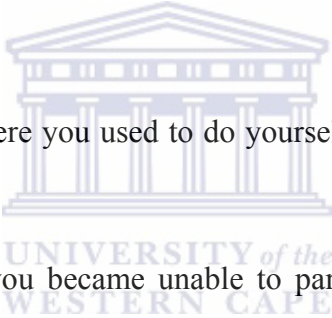
APPENDIX B

INTERVIEW GUIDE TO EXPLORE THE CHALLENGES EXPERIENCED BY STROKE PATIENTS

Please tell me about any problems you are having since you got stroke.

PROBES:
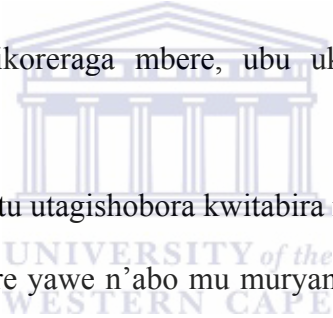
➢ Which activities were you used to do yourself, and which have been affected by stroke?

➢ Do you feel that you became unable to participate in any events after you experienced a stroke?

➢ Do you feel that your relationships with your family/other people have changed after the stroke? If so, how?

➢ How do people react towards your disease?

➢ Does your family/friends/society accept you?

➢ Are you accepted and supported by those around you?

➢ Do you have any obstacle in your daily life, or when you are walking if you can?

APPENDIX C

IBIBAZO BYIFASHISHIJWE MU RWEGO RWO GUSHAKA KUMENYA INGORANE ABARWAYI BA "STROKE" BAHURA NAZO.

Ndagira ngo umbwire ibibazo uhura nabyo nyuma yo kurwara "stroke".

UTUBAZO TWIHARIYE:

➢ Ni ibihe bintu wikoreraga mbere, ubu ukaba utakibishobora nyuma yo kurwara "stroke"?

➢ Ese ubona hari ibintu utagishobora kwitabira nyuma yo kurwara "stroke"?

➢ Ese ubona imibanire yawe n'abo mu muryango wawe cyangwa abandi bantu yarahindutse nyuma yo kurwara? Niba aribyo, ni gute yahindutse?

➢ Ese ubona abantu bakira gute uburwayi bwawe?

➢ Ni gute ubona umuryango wawe/ inshuti/ abavandimwe barakiriye uburwayi bwawe?

➢ Ese ubona abo mu muryango wawe, inshuti cyangwa se aho utuye bakwitaho?

➢ Ese mu buzima bwawe bwa buri munsi, nk'urugero iyo ugenda niba ubishobora, hari imbogamizi ujya uhura na zo?

Higher Degrees Committee
Faculty of Community and Health Sciences

10th November 2008

To whom it may concern:

Re: Research project of *Gerard Urimubenshi: Student Number: 2826534*

This letter confirms that Mr. Urimubenshi (student number: 2826534) is a postgraduate student in the Community and Health Sciences Faculty at UWC. His proposed research entitled, "*Profile of and challenges experienced by stroke patients admitted to Ruhengeri Hospital in Rwanda*", submitted in fulfilment of the requirements for Masters in Physiotherapy has been examined by the Higher Degrees Committee and found to be of high scientific value, methodologically sound and ethical.

We fully support the research and urge you to allow him access to your organisation.

Yours sincerely

Dr. G. Reagon
Chairperson Higher Degrees Committee

UNIVERSITY *of the*
WESTERN CAPE

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

APPENDIX E

REPUBLIQUE DU RWANDA

No. 09/ RNEC /2009

Date: 07th January 2009

Mr. Gerard Urimubenshi
University of the Western Cape

Your research Project: **Profile of and challenges experienced by stroke patients admitted to Ruhengeri hospital in Rwanda.**

Has been evaluated by the Rwanda National Ethics Committee.

Name	Institute	Involve in the decision		
			No (Reason)	
		Yes	Absent	Withdrawn from the proceeding
Dr. Kayitesi Kayitenkore	Medical Doctor, Dermatologist	X		
Prof.Bajyana Emmanuel	Immunologist, Dean of faculty of sciences (NUR)		X	
Dr. Nkeramihigo Emmanuel	Senior Lecturer, National University of Rwanda. Faculty of Medicine (NUR)	X		
Dr. Naasson Munyandamutsa	Medical Doctor, Psychiatrist		X	
Dr. Dariya Mukamusoni	Director of Nyamata Hospital	X		
Pastor. Elise Musemakweli	PhD Theology C/o. EPR Kigali, Rwanda		X	

1

After reviewing your protocol, during the RNEC meeting of December 13th 2008, where the quorum was met, and revisions made on the advice of the RNEC submitted On 05th January 2009, **we hereby provide approval for the above mentioned protocol**.

Please note that approval of the protocol and consent form is valid for 12 months.

You are responsible for fulfilling the following requirements:

1. Changes, amendments, and addenda to the protocol or consent form must be submitted to the committee for review and approval, prior to activation of the changes.

2. Only approved consent forms are to be used in the enrollment of participants

3. All consent forms signed by subjects should be retained on file. The RNEC may conduct audits of all study records, and consent documentation may be part of such audits.

4. A continuing review application must be submitted to the RNEC in a timely fashion and before expiry of this approval.

5. Failure to submit a continuing review application will result in termination of the study.

Sincerely,

Dr. Kayitesi KAYITENKORE.
CHAIR, Rwanda National Ethics Committee.

C.P.I.
- Hon. Minister of Health.
- The Permanent Secretary, Ministry of Health.

2

REPUBLIC OF RWANDA

Musanze,December10th 2008

**NORTHERN PROVINCE
MUSANZE DISTRICT**

N° ..../07.04.03

To: Director of Ruhengeri hospital
    Secretary Executive of Sector .... (All)
    Musanze District

**SUBJECT: Permission for Mr. URIMUBENSHI Gerard to conduct a research
study**

Dear Sir/Madam

With reference to the letter dated October 23 rd 2008 from the University of the Western
Cape South Africa requesting for the permission for **URIMUBENSHI Gerard**, a
Physiotherapy Master Student at the above mentioned University, to conduct a research
entitled **"Profile of and challenges experienced by stroke patients admitted to
Ruhengeri hospital in Rwanda"**.

We hereby ask you to facilitate him to carry his study scheduled from December 2008 to
January 2009.
Yours sincerely,

Celestin KARABAYINGA

Mayor of Musanze District

REPUBLIC OF RWANDA

MINISTRY OF HEALTH

MUSANZE DISTRICT

RUHENGERI HOSPITAL

02 December, 2008

Chairperson of National Ethics Committee of Rwanda

Kigali-Rwanda

Dear Sir/Madam

Re: Approval for Urimubenshi Gerard to conduct a research study

This letter is the approval for Urimubenshi Gerard, a Physiotherapy Master Student at the University of the Western Cape – South Africa, to conduct a research entitled "Profile of and challenges experienced by stroke patients admitted to Ruhengeri Hospital in Rwanda"

His proposed study is scheduled to take place during December 2008 and January 2009. We have no objection and fully support the research.

Yours sincerely

Dr KAIGAMBA R. Felix

Director of Ruhengeri hospital.

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

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

PARENTAL/GUARDIAN INFORMATION SHEET

Project Title: Profile of and challenges experienced by stroke patients admitted to Ruhengeri Hospital in Rwanda.

This is a research project being conducted by Gerard URIMUBENSHI at the University of the Western Cape. We are inviting your patiernt to participate in this research project as a person who has suffered a stroke. The purpose of this research project is to identify the profile of stroke patients admitted to Ruhengeri hospital in Rwanda from January 1st, 2005 up to December 31st, 2008. It also aims to determine the challenges experienced by stroke patients discharged from the Ruhengeri hospital. Whenever researchers study vulnerable groups like stroke patients, we talk to their parents/guardians and ask them for their permission. After you have heard more about the study, and if you agree, then the next thing we will do is ask your patient for his/her agreement as well. Both of you have to agree independently before we can begin.

The patient will be asked to participate in an interview which will last for about 40 minutes. This research project involves making audiotapes of him/her for further analysis of data. In addition, a research assistant will be used to take field notes, and he/she will sign a confidentiality form. Only the researcher will have access to audiotapes, and they will be destroyed after analysis (not later than October 2009).
By partaking in this study, the participant will not benefit financially.

To help protect his/her confidentiality, the rooms where the interviews will be conducted will be assessed prior to commencing the interviews, and all data collected from the interviews will be treated with great respect to ensure his/her privacy. In order to maintain anonymity in reporting data, every participant will get a code and confidentiality will be guaranteed. If we write a report or article about this research project, his/her identity will be protected to the maximum extent possible.

This research is not designed to help you or your patient personally, but the results may help the investigator learn more about stroke patients. We hope that, in the future, other people might benefit from this study through improved understanding of challenges experienced by stroke patients. Participation in this research is completely voluntary. The patient may choose not to take part at all, or if he/she decides to participate in this research, he/she may stop participating at any time, and he/she will not be penalized or loose any benefits to which he/she otherwise qualify.

The participant may have emotions during an interview on a devastating event of stroke that he/she experienced. If he/she is negatively affected by participating in this study, counseling will be provided to assist him/her.

This research is being conducted by Gerard URIMUBENSHI, a student in Physiotherapy Department at the University of the Western Cape. If you have any questions about the research study itself, please contact:

In Rwanda:
Gerard URIMUBENSHI

Muhoza Sector/ Musanze District/ Northern Province

Cell phone number: 08871371, E-mail: 2826534@uwc.ac.za

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

Chairperson of the Rwanda National Ethics Committee: Dr KAYITESI
KAYITENKORE
Ministry of Health
P.O. Box 84
Kigali, Rwanda
Phone: 55107884, E-mail: rnec@moh.gov.rw

 Or in South Africa:
Gerard URIMUBENSHI
University of the Western Cape
Private Bag X17, Bellville 7535
Cell phone number: 0027737443071, E-mail: 2826534@uwc.ac.za

Should you have any questions regarding this study and the rights of your patient as a
research participant or if you wish to report any problems you have experienced
related to the study, please contact:
Head of Department: Professor P. Struthers
Dean of the Faculty of Community and Health Sciences: Professor R. Mpofu
University of the Western Cape
Private Bag X17, Bellville 7535

This research has been approved by both the University of the Western Cape's Senate
Research Committee and Ethics Committee, and the Rwanda National Ethics
committee.

Researcher …………………………… ….**Date**………………………

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

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

PARTICIPANT INFORMATION SHEET

**Project Title: Profile of and challenges experienced by stroke patients admitted
to Ruhengeri Hospital in Rwanda.**

This is a research project being conducted by Gerard URIMUBENSHI at the University of the Western Cape. We are inviting you to participate in this research project as a person who has suffered a stroke. The purpose of this research project is to identify the profile of stroke patients admitted to Ruhengeri hospital in Rwanda from January 1st, 2005 up to December 31st, 2008. It also aims to determine the challenges experienced by stroke patients discharged from the Ruhengeri hospital.

You will be asked to participate in an interview which will last for about 40 minutes. This research project involves making audiotapes of you for further analysis of data. Only the researcher will have access to audiotapes, and they will be destroyed after analysis. By partaking in this study, you will not benefit financially. To help protect your confidentiality, the rooms where the interviews will be conducted will be assessed prior to commencing the interviews, and all data collected from the interviews will be treated with great respect to ensure your privacy. In order to maintain anonymity in reporting data, every participant will get a code and confidentiality will be guaranteed. If we write a report or article about this research project, your identity will be protected to the maximum extent possible.

This research is not designed to help you personally, but the results may help the investigator learn more about stroke patients. We hope that, in the future, other people might benefit from this study through improved understanding of challenges experienced by stroke patients. Your participation in this research is completely voluntary.

You may choose not to take part at all, or if you decide to participate in this research, you may stop participating at any time, and you will not be penalized or lose any benefits to which you otherwise qualify. You may have emotions during an interview on a devastating event of stroke that you experienced. If you are negatively affected by participating in this study, counseling will be provided to assist you.

This research is being conducted by Gerard URIMUBENSHI, a student in Physiotherapy Department at the University of the Western Cape. If you have any questions about the research study itself, please contact:

In Rwanda:
Gerard URIMUBENSHI
Muhoza Sector/ Musanze District/ Northern Province
Cell phone number: 08871371, E-mail: 2826534@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:
Chairperson of the Rwanda National Ethics Committee: Dr KAYITESI KAYITENKORE
Ministry of Health
P.O. Box 84
Kigali, Rwanda
Phone: 55107884, E-mail: rnec@moh.gov.rw

Or in South Africa:

Gerard URIMUBENSHI

University of the Western Cape

Private Bag X17, Bellville 7535

Cell phone number: 0027737443071, E-mail: 2826534@uwc.ac.za

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Head of Department: Professor P. Struthers

Dean of the Faculty of Community and Health Sciences: Professor R. Mpofu

University of the Western Cape

Private Bag X17, Bellville 7535

This research has been approved by both the University of the Western Cape's Senate Research Committee and Ethics Committee, and the Rwanda National Ethics committee.

Researcher …………………………… ….**Date**………………………

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

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

IBISOBANURIRWA UHAGARARIYE UGIRA URUHARE MU BUSHAKASHATSI

Ubushakashatsi: **Imiterere y'abarwayi ba "stroke" mu bitaro bya Ruhengeri mu Rwanda n'imbogamizi bahura nazo**

Ubu bushakashatsi burimo gukorwa na Gerard Urimubenshi, umunyeshuli wiga ubugororangingo muri kaminuza ya Western Cape, muri Afurika y'epfo. Turasaba umurwayi muhagarariye kugira uruhare muri ubu bushakashatsi kubera ko yujuje ibisabwa nabwo, nk'umuntu wahuye n'uburwayi bwa "stroke". Intego y'ubu bushakashatsi ni ukumenya Imiterere y'abarwayi ba "stroke" bivurije mu bitaro bya Ruhengeri mu Rwanda guhera muri Mutarama 2005 kugeza mu Kuboza 2008. Ubu bushakashatsi bugamije kandi kumenya imbogamizi abo barwayi bahura nazo. Abakora ubushakashatsi ku bantu bahuye n'ihungabana nk'abarwayi ba "stroke", bavugana n'ababashinzwe bakabasaba uburenganzira. Numara kumva ubu bushakashatsi ukemera ko umurwayi wawe yabugiramo uruhare, tuzakurikizaho gusaba umurwayi wawe ku giti cye kugira uruhare muri ubu bushakashatsi.

Umurwayi wawe arasabwa kugirana ikiganiro n'ukora ubushakashatsi ku bijyanye n'imbogamizi ahura nazo nyuma yo kurwara "stroke". Biramutwara igihe kingana n'iminota 40 tugereranyije. Birasaba ko amajwi ye afatwa kugira ngo tuzashobore kunonosora ibizava muri ubu bushakashatsi.

Ukora ubushakashatsi azifashisha umuntu wo kwandika ibivugirwa mu kiganiro,

kandi azasabwa kubahiriza ibanga. Ukora ubushakashatsi ni we wenyine uzagera kuri "cassettes" z'amajwi kandi zizasenywa nyuma yo kunonosora ibizava muri ubu bushakashatsi (bitarenze mu Kwakira 2009).

Tuzakora ibishoboka byose mu kumugirira ibanga. Kugira ngo tubamare impungenge, icyumba tuzakoreramo ikiganiro kigomba kuba cyujuje ibya ngombwa kugira ngo hatagira uwumva ibyo tuganira. Mu kwandika raporo y'ubu bushakashatsi, nta mazina y'umurwayi azakoreshwa, buri wese azaba afite "code" ye. Hagize inyandiko yandikwa kuri ubu bushakashatsi, azagirirwa ibanga rikomeye kubyo azaba yavuze byose.

Nta ngaruka n'imwe izwi yagirira muri ubu bushakashatsi. Nta nyungu y'amafaranga muzabona muri ubu bushakashatsi, ahubwo ibizavamo bizafasha ukora ubushakashatsi kongera ubumenyi ku barwayi ba "stroke". Twizeye kandi ko mu gihe kizaza abandi bantu bazagira inyungu kuri ubu bushakashatsi hashingiwe mu kumva neza imiterere y'abarwayi ba "stroke" n' imbogamizi bahura nazo kugira ngo zibe zabonerwa umuti. Kwemera kugira uruhare muri ubu bushakashatsi ni ubushake busesuye. Umuntu ashobora kwemera cyangwa kutemera kubugiramo uruhare. Yemerewe kwivana muri ubu bushakashatsi igihe cyose abishatse nta nkurikizi, ntazabihanirwa cyangwa ngo atakaze inyungu iyo ariyo yose yakagombye kubona. Haramutse habaye ikibazo cyamuhungabanya, hari umujyanama ubishinzwe wo kumufasha.

Ubu bushakashatsi burimo gukorwa na Gerard Urimubenshi, umunyeshuli wiga ubugorangingo muri kaminuza ya Western Cape, muri Afurika y'epfo. Ufite ikibazo kijyanye n'ubu bushakashatsi, wakwiyambaza:

Mu Rwanda:

Gerard URIMUBENSHI

Umurenge wa Muhoza/Akarere ka Musanze/Intara y'Amajyaruguru

Telefoni mobile: 08871371, E-mail: 2826534@uwc.ac.za

Hagize ikibazo cyose mwagira cyangwa mushatse kumenyekanisha ibibazo mwahuye nabyo birebana n'ubu bushakashatsi, mwakwiyambaza:

Umuyobozi wa Komite y'u Rwanda ishinzwe uburenganzira bw'abakorerwaho ubushakashatsi mu Rwanda:

 Dr KAYITESI KAYITENKORE

Minisiteri y'Ubuzima
Agasanduku k'iposita 84
Kigali, Rwanda
Telefoni: 55107884, E-mail: rnec@moh.gov.rw

Muri Afurika y'epfo
Gerard Urimubenshi
University of the Western Cape
Private Bag X17, Bellville 7535
Telefoni mobile: 0027737443071, E-mail: 2826534@uwc.ac.za

Hagize ikibazo cyose mwagira cyangwa mushatse kumenyekanisha ibibazo mwahuye nabyo birebana n'ubu bushakashatsi, mwakwiyambaza:
Uhagarariye ishami ry' ubugororangingo: Prof. Patricia Struthers
Umuyobozi wa Faculty of Community and Health Sciences: Prof. Ratie Mpofu
University of the Western Cape
Private Bag X17, Bellville 7535

Ubu bushakashatsi bwemejwe na Sena ya Kaminuza ya Western Cape ishinzwe ubushakashatsi, ndetse na Komite y'iyo Kaminuza ishinzwe iyubahirizwa ry'ikiremwa muntu mu bushakashatsi.Ubu bushakashatsi kandi bwemejwe na Komite ishinzwe uburenganzira bw'abakorerwaho ubushakashatsi mu Rwanda.

Ukora ubushakashatsi…………………………………......Italiti……………..

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IBISOBANURIRWA UGIRA URUHARE MU BUSHAKASHATSI

Ubushakashatsi: **Imiterere y'abarwayi ba "stroke" mu bitaro bya Ruhengeri mu Rwanda n'imbogamizi bahura nazo.**

Ubu bushakashatsi burimo gukorwa na Gerard Urimubenshi, umunyeshuli wiga ubugororangingo muri kaminuza ya Western Cape, muri Afurika y'epfo. Murasabwa kugira uruhare muri ubu bushakashatsi kubera ko mwujuje ibisabwa nabwo, nk'abantu bahuye n'uburwayi bwa "stroke". Intego y'ubu bushakashatsi ni ukumenya Imiterere y'abarwayi ba "stroke" bivurije mu bitaro bya Ruhengeri mu Rwanda guhera muri Mutarama 2005 kugeza mu Ukuboza 2008. Ubu bushakashatsi bugamije kandi kumenya imbogamizi abo barwayi bahura nazo.

Urasabwa kugirana ikiganiro n'ukora ubushakashatsi ku bijyanye n'imbogamizi uhura nazo nyuma yo kurwara "stroke". Biragutwara igihe kingana n'iminota 40 tugereranyije. Birasaba ko amajwi yawe afatwa kugira ngo tuzashobore kunonosora ibizava muri ubu bushakashatsi. Ukora ubushakashatsi ni we wenyine uzagera kuri "cassettes" z'amajwi kandi zizasenywa nyuma yo kunonosora ibizava muri ubu bushakashatsi. Tuzakora ibishoboka byose mu kukugirira ibanga. Kugirango tukumare impungenge, icyumba tuzakoreramo ikiganiro kigomba kuba cyujuje ibya ngombwa kugira ngo hatagira uwumva ibyo tuganira. Mu kwandika raporo y'ubu bushakashatsi, nta mazina yawe azakoreshwa, buri wese azaba afite "code" ye.

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Hagize inyandiko yandikwa kuri ubu bushakashatsi, uzagirirwa ibanga rikomeye kubyo wavuze byose.

Nta ngaruka nimwe izwi wagirira muri ubu bushakashatsi. Nta nyungu y'amafaranga uzabona muri ubu bushakashatsi, ahubwo ibizavamo bizafasha ukora ubushakashatsi kongera ubumenyi ku barwayi ba "stroke".

Twizeye kandi ko mu gihe kizaza abandi bantu bazagira inyungu kuri ubu bushakashatsi hashingiwe mu kumva neza imiterere y'abarwayi ba "stroke" n' imbogamizi bahura nazo kugira ngo zibe zabonerwa umuti. Kwemera kugira uruhare muri ubu bushakashatsi ni ubushake bwawe busesuye. Ushobora kwemera cyangwa kutemera kubugiramo uruhare. Wemerewe kwivana muri ubu bushakashatsi igihe cyose ubishatse nta nkurikizi, ntuzabihanirwa cyangwa ngo utakaze inyungu iyo ariyo yose wakagombye kubona. Haramutse habaye ikibazo cyaguhungabanya, hari umujyanama ubishinzwe wo kugufasha.

Ubu bushakashatsi burimo gukorwa na Gerard Urimubenshi, umunyeshuli wiga ubugorangingo muri kaminuza ya Western Cape, muri Afurika y'epfo. Ufite ikibazo kijyanye n'ubu bushakashatsi, wakwiyambaza:

Mu Rwanda:

Gerard URIMUBENSHI

Umurenge wa Muhoza/Akarere ka Musanze/Intara y'Amajyaruguru

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Hagize ikibazo cyose wagira cyangwa ushatse kumenyekanisha ibibazo wahuye nabyo birebana n'ubu bushakashatsi, wakwiyambaza:

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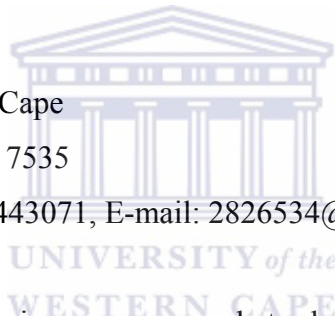
Telephone: (250) 55107884, E-mail: rnec@moh.gov.rw

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Ukora ubushakashatsi………………………...………………..Italiti…………….

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PARENTAL/GUARDIAN CONSENT FORM

Title of Research Project: Profile of and challenges experienced by stroke patients admitted to Ruhengeri Hospital in Rwanda

I have been asked to give consent for my patient to participate in this research study which will involve him/her completing an interview. I understand that he/she will also be asked to give permission and that his/her wishes will be respected. I have been informed that the risks are minimal and may include only emotions, and in this case counseling will be provided to assist him/her. I am aware that there may be no benefit to either my patient or me personally. I have been provided with the name of a researcher who can be easily contacted using the number I was given for that person.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction. I consent voluntarily for my patient to participate as a participant in this study and understand that I have the right to withdraw him/her from the study at any time without in any way affecting our care.

Name of Parent or Guardian ……………………………………………………..

Signature or Thumb print of Parent of Guardian…………………………………

Date (Day/month/year)……………………………………………………………

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Name of witness………………………………………………………………………

Signature of witness ……………………………………………………………………

Date (Day/month/year)………………………………………………………………….

I have accurately read or witnessed the accurate reading of the consent form to the parent/guardian of the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Name of researcher……………………………………………………………………

Signature of researcher…………………………………………………………………

Date (Day/month/year)…………………………………………………………………
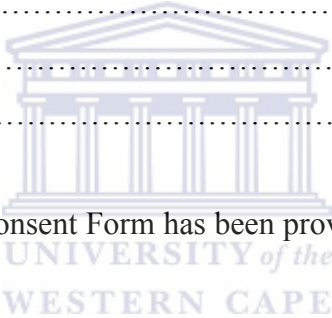
A copy of this Informed Consent Form has been provided to the parent or guardian of the participant.

An Informed Assent Form will be completed.

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PARTICIPANT CONSENT FORM

Title of Research Project: Profile of and challenges experienced by stroke patients admitted to Ruhengeri Hospital in Rwanda

The study has been described to me in a language that I understand and I freely and voluntarily agree to participate. I agree to be audiotaped during my participation in this study. 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.

Name of participant…………………………...........................……………………

Signature/Thumb print of participant................................……………………….

Date (Day/month/year)....………..

I have witnessed the accurate reading of the assent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given assent freely.

Name of witness …………………………………………………………………

Signature of witness ………………………………………………………………..

Date (Day/month/year) ...………..

I have accurately read or witnessed the accurate reading of the assent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given assent freely.

Name of researcher...

Signature of researcher..

Date (Day/month/year) ....………...

A copy of this Assent Form has been provided to the participant.

Parent/Guardian has signed an informed consent.

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ICYEMEZO CYO KWEMERA KUGIRA URUHARE MU BUSHAKASHATSI CY'UHAGARARIYE UGIRA URUHARE MU BUSHAKASHATSI

Ubushakashatsi: **Imiterere y'abarwayi ba "stroke" mu bitaro bya Ruhengeri mu Rwanda n'imbogamizi bahura nazo**

Nasabwe ko umurwayi mpagarariye agira uruhare muri ubu bushakashatsi, agirana ikiganiro n'ukora ubwo bushakashatsi. Numvise ko ku giti cye nawe azasabwa kwemera kubugiramo uruhare kandi ko ibyifuzo bye bizubahirizwa. Nabwiwe kandi ko nta ngaruka ihari uretse kuba yagira ikibazo cyamuhungabanya, kandi ko hateganyijwe umujyanama wo kumufasha biramutse bibaye. Namenyeshejwe ko nta nyungu njye n'umurwayi wanjye tuzavana muri ubu bushakashatsi. Nahawe amazina na nimero za telefoni nakwifashisha mu kugira icyo mbaza kijyanye n'ubu bushakashatsi. Nasomye cyangwa nasomewe ibijyanye n'ubu bushakashatsi, kandi nahawe umwanya wo kubaza no gusobanuza, kandi ibibazo byanjye byose byasubijwe. Nemeye ko umurwayi mpagarariye agira uruhare muri ubu bushakashatsi kandi numvise ko mfite uburenganzira bwo kumuvana muri ubu bushakashatsi igihe icyo ari cyo cyose mbishatse nta zindi nkurikizi.

Amazina y'uhagarariye ugira uruhare mu bushakashatsi..

Umukono/Igikumwe cy'uhagarariye ugira uruhare mu bushakashatsi...........................

Italiki (umunsi/ukwezi/umwaka)..

Ntanze ubuhamya ko nasomye neza ibisobanurirwa uhagarariye umurwayi ugira uruhare muri ubu bushakashatsi, kandi ko yahawe umwanya wo kubaza ibibazo afite. Nemeje ko yemeye ku giti cye ko umurwayi ahagarariye agira uruhare muri ubu bushakashatsi.

Amazina
y'umuhamya...
Umukono
w'umuhamya..
Italiki
(umunsi/ukwezi/umwaka)...

Nemeje ko nasomye neza cyangwa ko hasomwe neza ibisobanurirwa uhagarariye umurwayi ugira uruhare muri ubu bushakashatsi, kandi ko yahawe umwanya wo kubaza ibibazo afite.
Nemeje ko yemeye ku giti cye ko umurwayi ahagarariye agira uruhare muri ubu bushakashatsi.
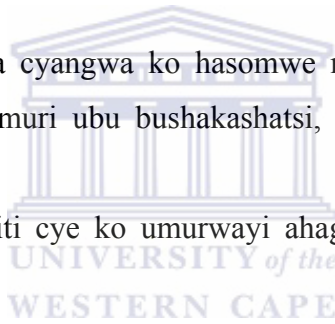
Amazina y'ukora ubushakashatsi...
Umukono w' ukora ubushakashatsi...
Italiki (umunsi/ukwezi/umwaka)..

Kopi y'urupapuro rw'ibisobanurirwa uhagarariye umurwayi yahawe uhagarariye umurwayi ugira uruhare muri ubu bushakashatsi.
Umurwayi ugira uruhare muri ubu bushakashatsi nawe arasabwa ku giti cye kwemera kugira uruhare muri ubu bushakashatsi.

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KWEMERA KUGIRA URUHARE

Ubushakashatsi: **Imiterere y'abarwayi ba "stroke" mu bitaro bya Ruhengeri mu Rwanda n'imbogamizi bahura nazo**

Nyuma yo gusobanurirwa iby'ubu bushakashatsi n'ibijyanye nabwo mu rurimi numva, kandi ko bazangirira ibanga ku byo nzavuga byose, no kuba nemerewe kwivana muri ubu bushakashatsi igihe cyose mbishatse kandi ko nta nkurikizi byangiraho, nemeye ku bushake bwanjye kugira uruhare muri ubu bushakashatsi. Nemeye kandi gufatwa amajwi mu kiganiro ngirana n'ukora ubushakashatsi.

Amazina y'ugira uruhare mu bushakashatsi...

Umukono/Igikumwe cy' ugira uruhare mu bushakashatsi..

Italiki (umunsi/ukwezi/umwaka)..

Ntanze ubuhamya ko nasomye neza ibisobanurirwa ugira uruhare muri ubu bushakashatsi, kandi ko yahawe umwanya wo kubaza ibibazo afite.

Nemeje ko yemeye ku giti cye kugira uruhare muri ubu bushakashatsi.

Amazina y'umuhamya...

Umukono w'umuhamya...

Italiki (umunsi/ukwezi/umwaka)...

1

Nemeje ko nasomye neza cyangwa ko hasomwe neza ibisobanurirwa ugira uruhare muri ubu bushakashatsi, kandi ko yahawe umwanya wo kubaza ibibazo afite.

Nemeje ko yemeye ku giti cye kugira uruhare muri ubu bushakashatsi.

Amazina y'ukora ubushakashatsi..

Umukono w' ukora ubushakashatsi..

Italiki (umunsi/ukwezi/umwaka)...
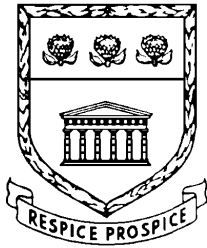
Kopi y'urupapuro rw'ibisobanurirwa ugira uruhare mu bushakashatsi yahawe ugira uruhare muri ubu bushakashatsi.

Uhagarariye ugira uruhare muri ubu bushakashatsi yemeye ko uwo ahagarariye agira uruhare muri ubu bushakashatsi.

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RESEARCH ASSISTANT CONFIDENTIALITY AGREEMENT FORM

Title of Research Project: Profile of and challenges experienced by stroke patients admitted to Ruhengeri Hospital in Rwanda

I,.., the research assistant, have been hired to assist the Researcher to collect data from medical records and take notes during the interview with the research participants. I agree to:

1. Keep all the research information shared with me confidential by not discussing or sharing the research information in any form or format (e.g. including but not limited to tapes, transcripts) with anyone other than the Researcher.

2. Return all research information in any form or format (e.g. including but not limited to tapes, transcripts) to the Researcher when I have completed the research tasks.

3. After consulting with the Researcher, erase or destroy all research information in any form or format regarding this research project that is not returnable to the Researcher (e.g. including but not limited to information stored on computer hard drive, note books).

4. Maintain anonymity and confidentiality of the study participants.

…………………………………………………   ……………………….   ………………..

(Name)   (Signature)   (Date)

Research Assistant

…………………………………………………   ……………………….   ………………..

(Name)   (Signature)   (Date)

Researcher