PERCEIVED NEEDS AND EXPERIENCES OF INFORMAL CAREGIVERS OF ADULT STROKE SURVIVORS POST-DISCHARGE IN LUSAKA

BY

OSWELL KHONDOWE
STUDENT NUMBER: 2257702

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Faculty of Community and Health Sciences

The University of the Western Cape, Bellville, South Africa

Supervisors:

Professor Ratie Mpofu

Mrs. Anthea Rhoda

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DECLARATION

I hereby declare that "perceived needs and experiences of informal caregivers of adult stroke survivors post-discharge in Lusaka" is my own work and that I have not submitted it or any part of it for a degree at any other university. All the sources I have used or quoted have been indicated and acknowledged by means of complete reference.

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OSWELL KHONDOWE

DATE

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ABBREVIATIONS

ADLS	ACTIVITIES OF DAILY LIVING
AHA	AMERICAN HEART ASSOCIATION
B1-5	FIVE-ITEM BARTHEL INDEX
CGSQ	CAREGIVER STRAIN QUESTIONNAIRE
CSI	CAREGIVER STRAIN INDEX
CSO	CENTRAL STATISTICS OFFICE
HIV	HUMAN IMMUNO-DEFFICIENCY VIRUS
AIDS	ACQUIRED IMMUNO-DEFFICIENCY SYNDROME
ICF	INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH
SPSS	STATISTICAL PACKAGE FOR SOCIAL SCIENCES
TM/HBPC	TEAM-MANAGED, HOME-BASED PRIMARY CARE
UK	UNITED KINGDOM
UNICEF	UNITED NATIONS INTERNATIONAL CHILDREN'S FUND
USA	UNITED STATES OF AMERICA
UTH	UNIVERSITY TEACHING HOSPITAL
WHO	WORLD HEALTH ORGANIZATION

KEY WORDS

Informal caregivers

Experiences

Needs

Information and communication

Economic burden

Daily routine

Support

Gender

Physical and Emotional health

ABSTRACT

Stroke is a serious health problem in both developing and developed countries. It is estimated that more than one-half of stroke survivors are left with residue disabilities that require assistance with activities of daily living, such as, eating, bathing and dressing. Family or community members who volunteer to provide the assistance in activities of daily living for the disabled are referred to as informal caregivers. The main aim of this study is to identify the expressed needs and experiences of informal caregivers of adult stroke patients attending physiotherapy sessions at University Teaching Hospital (UTH) in Lusaka and investigate factors influencing them.

Seventy informal caregivers of stroke patients attending the out-patient physiotherapy department were recruited for this study. A cross-sectional descriptive study design utilizing a questionnaire with closed items and another with open items administered by the researcher are used in the present study. Ethical clearance was obtained from the Higher Degrees committee of the University of the Western Cape's Faculty of Community Health Science.

The Statistical Package for Social Sciences (SPSS) and Statistical Analysis System (SAS) were used in order to obtain frequencies, cross tabulations and correlations. Interviews using the questionnaire with open-ended items were tape-recorded and transcribed *verbatim*. Transcribed data were reduced into categories and categories into themes. The themes that were more frequent were information of stroke rehabilitation and knowledge about stroke, discontinuity of caregiver's daily routine, need for support services, work overload, need for community centred programmes, need for finances, views on physiotherapy rehabilitation services and need for respite care.

The results reflected a significantly younger age group of stroke patients and informal caregivers compared to literature reviewed. Seventy-one point seven percent of the caregivers interviewed were females and 28.3% were males. The majority of the caregivers were in good health. The experience of caring had mixed outcomes that were positive, negative and reciprocal. Difficulties in transporting the patient to the hospital on a weekly basis, the patient's change in behaviour, financial difficulties, isolation and non-involvement in the rehabilitation process were negative experiences. Informal caregivers were concerned about the limited time given to patients during sessions and being isolated and abandoned. The most expressed needs were for information, finances, community support workers and respite care.

This study may help physiotherapists learn to be more aware of the needs and experiences of informal stroke caregivers attending out patient physiotherapy sessions and as such, will develop strategies to meet these needs and experiences. The findings of this study provides information, which could be used by rehabilitation professionals, especially physiotherapist, to implement or adjust rehabilitation programmes to include the needs of the caregivers of stroke patients.

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CHAPTER 1

INTRODUCTION

1.1 INTRODUCTION

The present chapter provides information relating to the background and the overall aim of the study. The objectives used to fulfill the aim are specified and the significance of the study is explained. The definitions of terms used in the study are provided together with an overview of the chapters of the thesis.

1.2 BACKGROUND

Stroke is a serious health problem in both developing and developed countries (Dowswell, Dowswell, Lawler, Green & Young, 2002; Giacaman, 2001). It is recognized as a major cause of death and disability (Bakas, Austin, Okonkwo, Lewis & Chadwick, 2002). In the United Kingdom (UK) it is estimated that 200 people in a population of 100,000 suffer a stroke each year (Wade, 1994). More than one-half of stroke survivors are left with residual disabilities that require assistance with activities of daily living, such as, eating, bathing and dressing (Dorsey & Vaca, 1998; AHA, 1995; Wade, 1994). The functional deficits that may occur after a stroke could result in the affected individuals being dependent on others for essential care (Vanetzian & Corrigan, 1995). Those who provide the assistance with the activities of daily living for the disabled person on a voluntary basis are referred to as informal caregivers (Anderson, Linto & Stewart-Wynne 1995).

Family members, who are not paid or trained by a statutory body, such as children and spouses, routinely accept the major role of care giving (Pollock-Hoeman, 1992). Typically, they accept the role of care giving in the event of nobody else being available to provide the care or they are not able to employ someone, and not because they are proficient or feel comfortable with the type of care required. Culturally, in an African perspective, it is expected that a relative will take up the responsibility of care giving for the person with a disability. The caregivers frequently accept or are expected to assume their role without regard for the possible emotional, physical, and financial consequences (Kasuya, Polgar-Bailey, Takeuchi, 2000).

As stroke is a sudden event, caregivers of stroke patients are forced to accept a large amount of unforeseen responsibilities in the absence of preparation. In addition to this, the care giving role has various other implications for the caregiver. These include future plans being shattered, present income generating activities being abandoned, a decrease in leisure time and susceptibility to a deteriorating health status (Dowswell, Lawler, Dowswell, Young, Forster & Hearn, 2000; WHO Technical Report, 2000; Fritz, 1997). In the process of care giving, the abilities of the caregivers to provide for their own emotional, personal, physical, social and financial needs are seriously compromised (WHO Technical Report, 2000; Fritz, 1997).

According to Bakas et al, (2002) needs of caregivers include general information about the warning signs for stroke, lifestyle changes for the stroke survivor, and the management of stroke-related symptoms and complications.

The researcher's past experience in hospital and community settings in Lusaka, Zambia motivated this thesis. His experience included rehabilitation of stroke and cerebral palsy patients at the University Teaching Hospital (UTH) in Lusaka and in the community. Physiotherapists' role in stroke rehabilitation has largely focused on patient assessment, diagnosis, treatment and reassessment. Interacting with the caregivers of stroke and cerebral palsy patients made the researcher aware of the difficulties the caregivers experienced with no direct assistance and support for them. In communities, especially in developing countries only few referral services for stroke patients and their caregivers exist (Mitchell, 1999).

The past few years have seen a significant increase in the number of stroke patients attending physiotherapy in Zambia. This could have increased the number of people needing care as a result of them having suffered a stroke. Caregiver characteristics, especially age and economical status, could be influenced by the increased death rate of the younger population, especially as a result of the HIV/AIDS pandemic. The life expectancy in Zambia is estimated to have dropped to 38 years in 2002 (UNICEF, 2002) from 42 in the year 2000 (Central Statistics Office, 2001).

1.3 PROBLEM STATEMENT

Stroke is a worldwide major problem. It causes disability and creates a greater need for caregivers. After initial hospitalization, 80% of stroke survivors return to the community, relying on their family members' emotional, informational, and instrumental support for daily living (Anderson et al., 1995). In the process the caregivers' lives are interrupted in various area such as, family responsibilities, education, social activities, leisure time and work. Few studies have been done in mostly developed countries on needs and experiences of caregivers for stroke patients but none have been conducted in Zambia.

There has been an increase in the number of stroke patients attending the out-patient department at the University Teaching Hospital (UTH) in Lusaka, Zambia. Therefore, a need arises to undertake a study to establish the characteristics, needs and experiences of the informal caregivers for stroke patients at UTH.

1.4 AIM OF THE STUDY

The aim of this study is to identify the perceived experiences and needs of informal caregivers of stroke patients who attend physiotherapy sessions as out-patients at the University Teaching Hospital (UTH) in Lusaka.

1.5 SPECIFIC OBJECTIVES

The objectives of this study were;

1. To determine the informal caregiver's socio-demographic characteristics.
2. To determine the perceived health status of informal caregivers.
3. To determine the experiences and needs of informal caregivers when caring for stroke patients.
4. To investigate factors that influence perceived experiences and needs of informal caregivers.
5. To make recommendations regarding the needs and experiences of caregivers.

1.6 SIGNIFICANCE OF THE STUDY

Despite the high prevalence of stroke and the potentially high burden on caregivers of the stroke survivors worldwide, a few studies have systematically addressed the consequences of stroke on family members and other informal caregivers (Wolfe, Rudd & Beech, 1996; Periad & Ames, 1993). Eaves (2002) states that stroke rehabilitation at present, mainly addresses the needs of the patient and little attention is given to the needs of the caregivers of these patients. To date, there is no documented information regarding the experiences and needs of informal caregivers of stroke patients in Zambia. The present study therefore aims to provide the information regarding the experiences and needs of informal caregivers, which could be used by rehabilitation professionals, especially physiotherapists, to implement or adjust rehabilitation programmes to include the needs of the caregivers of stroke patients.

1.7 DEFINITION OF TERMS:

Clinical Depression: This is a mental state characterized by feelings of sadness, hopelessness, and loss of interest, experienced by most individuals (Marshal, 1996).

Disability: In the International Classification of Functioning, Disability and Health (ICF), disability serves as an umbrella term for impairment, activity limitations and participation restrictions in relation to contextual and environmental factors (WHO, 2001).

Informal Caregiver: may be a relative or neighbour or friend most closely involved with the patient's ability to function independently in the home (Teel, Duncan & Lai, 2001).

Stress is defined as physical and psychological strain, usually lasting for a period of time, which threatens the ability of a person to continue coping with a given situation (Statt, 1998).

Stroke: is defined as "a focal (or at times global) neurological impairment of sudden onset, and lasting more than 24 hours (or leading to death) and of presumed vascular origin" (WHO, 1989).

1.8 OUTLINE OF CHAPTERS

Chapter one outlines the background of the study emphasizing the burden of stroke and the increasing need for the role of informal caregivers in stroke rehabilitation. The need for information relating to needs and experiences of caregivers in Lusaka, Zambia is emphasized.

Chapter two presents a review of relevant literature to conceptualize the present study. Literature relating to stroke, specifically the needs and experiences of informal caregivers of stroke patients, is reviewed.

Chapter three explains the methodology used in the present study. The research setting, instruments used, procedure, data analysis and ethical considerations are explained.

Chapter four presents the outcome of the analysis of the data collected. The demographic results are graphically presented in frequencies, percentages and means. Correlations made between certain variables are also presented. Data from open-ended questions are presented in the form of narratives.

Chapter five discusses the whole study and includes the findings with regards to socio-demographic data of caregivers and their patients, the caregivers' health status, experiences as caregivers and their needs and factors that influence care giving.

Chapter 6 summarizes the study, some conclusions are drawn, and recommendations are made. Limitations encountered during the execution of the study are presented.

CHAPTER 2

2.1 INTRODUCTION

The literature reviewed in the present study will be presented in this chapter. It includes definition of stroke, informal caregivers, characteristics of caregivers, experiences of caregivers, health status, needs of caregivers and factors influencing caregivers' experiences and needs.

2.2 DEFINITION OF STROKE

Stroke is defined as an acute neurological dysfunction of vascular origin with rapidly developed clinical signs of focal or global disturbance of cerebral function lasting more than 24 hours (WHO, 1989). A stroke may be caused by cerebral haemorhage, thrombosis or embolism with similar signs and symptoms except for the onset, which usually gives a clue as to what the cause is (Kahn, 2003). Stroke often results in paralysis on one side of the body or death. The paralysis results in the patient failing to perform some activities of Daily Living (ADLs) such as walking, bathing, dressing and feeding (Eaves, 2002). Due to stroke patients having problems in performing certain functional activities, there is a need for caregivers to help in achieving the activities.

2.3 INFORMAL CAREGIVERS OF STROKE PATIENTS

There are mainly two types of caregivers, informal and formal caregivers. Formal caregivers are trained health personnel or individuals who care for a sick, elderly or disabled person. An informal caregiver is a relative, friend or neighbour most closely involved with the patient's ability to function independently in the home (Teel et al., 2001). Informal caregivers are usually family members who are not paid to provide the services. They are an important resource in the promotion of both successful health outcome in stroke survivors and a more cost-effective use of health and social service resources (Low, Payne & Roderick, 1999).

Studies have revealed that stroke in the United Kingdom (UK) represents a major discontinuity in the lives of caregivers (Dowswell et al., 2000; Henwood, 1998; Warner & Wexler, 1998). In the UK informal caregivers providing or intending to provide "regular and substantial care" have a statutory right to an assessment of their needs, as defined in law by the caregivers (Department of Health and Social Services Inspectorate, 1996). Despite the greater recognition now given to caregivers' needs, several recent studies in the UK have indicated that these remain poorly addressed (Banks, 1999; Henwood, 1998; Warner & Wexler, 1998). This is due, in part, to the lack of an explicit service model and the failure to conceptualize the intended goals of caregiver support adequately (Twigg & Atkin, 1994; Askham, 1998). Neal, Ingersoll and Starrells (1997) reported that 2.2 million Americans are caregivers for elderly and disabled persons. Not much has been documented on stroke caregiving in developing countries.

2.4 CAREGIVER CHARACTERISTICS

Characteristics of caregivers in the literature review were related to gender, age, economic and health status, and these will be discussed below.

Giacaman (2001) finds that in a Palestinian context, care giving especially of the disabled, elderly and the sick, is a predefined, gender-linked role dictated by a patriarchal society and system of policy making that excludes women from economic and social life. The "feminization of care giving," that is, the societal expectation that women will be caregivers, has resulted in women providing care in over 75% of cases and the remaining 25%, male caregivers, are often inadequately prepared for the role (Kasuya et al., 2000). Many studies have recorded major gender imbalances in apportioning care-giving roles, with females assuming the care-giving role more than their male counterparts (Gräsel, 2002; Van der Smagt-Duijnstee, Hamers, Abu-Saad & Zuidhof, 2001; Dennis, O'Rourke, Lewis, Sharp, & Warlow, 1998; Anderson et al., 1995). The societal expectation of Women having always to take care of the sick relative causes greater impact of communal care on the already burdened lives of women, especially when such care is expected to be voluntary in nature (Giacaman, 2001). In a study by Kerr & Smith (2001), 63% of the caregivers were wives while 22.5% were daughters of the patients. It is unlikely that these expectations of women to be the caregivers will ever be seriously challenged in developing countries. So entrenched is the idea that men must fend for their families and women must nurture.

It has been found that the majority of caregivers are elderly. Gräsel, (2002) and Kerr & Smith (2001) reported mean ages of 58.1 and 61 respectively, for informal caregivers in the United States of America (USA). Care giving affects people differently according to their age. Younger caregivers are forced to abort future plans, while older ones are overburdened owing to poor health exacerbated by the aging process (Van den Heuvel, de Witte, Schure, Sanderman & Meyboom-de Jong, 2001). The societal expectations for youth are that of productivity. Assuming a care-giving responsibility means abandoning many plans as a result of its confining nature. Moreover, old age is naturally accompanied by illness. Assuming care-giving roles can be physically straining and this may cause the health status of the elderly to deteriorate. With the advent of HIV/AIDS however, the life expectance in Zambia has dropped significantly to 38 years and it is therefore expected that the care giving role will be assumed mostly by the youth (Schlein, 2003).

The main issues of concern with regard to the social and economic aspects are alteration of social relations with friends, social isolation and lack of finances, particularly in countries such as Zambia where social security funds for the disabled and caregivers are nonexistent. Stroke care giving demands an increase in finance in areas related to rehabilitation especially in communities where there exists no community rehabilitation programmes. Funds are needed for transportation, hospital fees, medication and sometimes, a special diet. The ones affected the most are those in the middle and lower economic classes.

Bowling (2000) argues that those in the higher socio-economic groups are more likely to pursue healthy life styles than those in the lower socio-economic groups. This is largely because they are able to afford costs for medication. Life style is determined partly by a person's access to financial resources to support the chosen lifestyle (Bowling, 2000). Zwygart-Stauffacher, Lindquist and Savik (2000) agree that stroke contributes to a substantial economic burden for the stroke caregiver. Financial problems are most relevant among families, especially where the main wage earner suffers a stroke or takes up the care-giving role (Anderson et al., 1995).

Some caregivers suspend their employment or end up working part-time in order to take care of the affected spouse or family member. This adds more strain on their already tight budget. Van den Heuvel et al, (2001) states that in developed countries the majority of caregivers' socioeconomic status is middle class. The tremendous demands of care giving results in the lives of caregivers often revolving exclusively around the needs of the loved ones. This excludes them from social functioning.

2.5 HEALTH STATUS

Widén, De Pedro, Moller, Holm, and Siden (1996) found that caregiving of a patient with stroke affects the caregivers by causing their health status to deteriorate. Health of caregivers is an important factor in determining how easily the caregiver may perform the role of care giving. According to Low et al, (1999) there are a few studies that have focused on the health of caregivers of stroke patients. Schultz, Tompkins, and Rau (1988) stated that caregivers' concerns about their poor health are a significant predictor of depression. It is assumed that a caregiver with poor health may find it more difficult than one who is in good health to carry out tasks to help the patient in activities such as transfers or transporting the patient to the clinic. The majority of studies have addressed the health of the caregiver focusing on psychological health (Low et al., 1999 and Lilley, Lincoln, & Francis, 2003). Low et al, (1999) pointed out that many studies have measured caregivers' functional and physical aspects of their health using non-standardized subjective measures such as self-reported responses. Low et al, (1999) emphasized the need for a shift in research away from a purely psychological approach to the evaluation of a more global concept of quality of life, incorporating the physical, psychological, social and functional dimensions.

2.5.1 PHYSICAL HEALTH

Following discharge, providing daily care to a stroke patient needing help in carrying out various ADLs is a physically and emotionally exhausting task (Bressick & Harvey, 1997). In more severe cases, the physical health of the caregiver may be affected (Bressick & Harvey, 1997).

There is a great need for caregivers to be physically healthy in order to provide sufficient care to stroke patients. The need for health becomes critical when dealing with patients with lower functional levels. Grant, Elliot, Giger & Bartolucci

(2000) find that poor physical health negatively influences the emotional well-being of caregivers of stroke patients.

In Bakas et al, (2002) confirm that caregivers report a need for personal attention to maintain their own physical health needs. The physical health needs of caregivers have been addressed inadequately by health workers (McLean, Roper-Hall, & Mayer, 1991). Physiotherapists and other health professionals can assist caregivers to maintain the caregivers' health by teaching them principles of back care such as lifting and transfer techniques and other energy-saving methods (Bressick & Harvey, 1997).

2.6 EXPERIENCES OF CAREGIVERS

The continuing shift from institutional care to community care makes the impact of stroke care giving profound as the care of the patient shifts from the health professionals to the family members (Han & Haley, 1999). Many anxieties among caregivers develop upon discharge from the hospital. Usually the magnitude of the burden of caring is not felt by the caregiver whilst the patient is in the hospital as there are many professionals around the patient, such as nurses and physiotherapists. When the patients get home, the reality of the depth of the situation begins to dawn with sometimes serious results (Kerr & Smith, 2001). Finn (1994) reports that caregivers feel abandoned and isolated after the patient has been discharged from hospital as the expectations of continued support after discharge are largely unmet.

Literature presents various examples of how the caregivers react and feel about their experiences as caregivers. In a study by Finn (1994), a wife of a disabled husband said the following words in regards to her experience, "*let me put it this way; if I could live my life again I would say no… I wouldn't have one day of it.*"

According to Dowswell et al, (2000) informal caregivers take up responsibilities that were not anticipated. Their lives are changed as they strive to include the daily challenges of caring into their lives. According to a caregiver, as cited in Dowswell et al, (2000)... "*It's ruined my life, I am helpless…absolutely. There is nothing you can do. And afterwards you can just help as much as you can and that's it. I am, sorry [crying] … Life has just really more or less come to a stand still… …It's not going to go back to the same as before… …It never will.*" The quotation confirms that there is very little time for family members to prepare for a caring role (Brereton & Nolan, 2002).

Studies have shown that stroke caregivers have poorer psychological health than the general population due to factors such as the severity of the physical disability, the quality of the caregiver-survivor relationship, and the extent of the cognitive and behavioural abnormality resulting from the stroke, associated with psychological morbidity (Low et al., 1999; Gräsel, 2002; Han & Haley, 1999). Informal caregivers often sacrifice family relationships, friendships, and participation in other activities, and these results in psychological health problems such as stress. Anderson et al, (1995) highlighted emotional ill health, disruption of social activities and leisure time as the most affected by care giving for stroke patients. Out of the 84 caregivers included in the quantitative study, 35% of them reported adverse effects on family relationships for a variety of reasons that included tension, misunderstandings, or feeling of neglect among family members because of the physical and emotional demands of the patient.

Stress may occur when family members are faced with the constant demands of caring for a chronically ill family member. Taking care of a stroke patient can have negative emotional consequences for the family caregiver, which can in turn, have negative implications for continuation of the care giving role (Teel et al., 2001; Bressick & Harvey, 1997). The main effects of care giving, described in Finn (1994) and Bressick & Harvey (1997), are stress and poor health (mainly worry, exhaustion and mental strain). Others are: anxiety over whether they are providing the best care, frustration that they could not restore function and anger at disruption of their lives' daily routine. Caring for a physically disabled spouse or other relative can be physically and emotionally stressful, placing the caregiver at heightened risk of illness and the onset of chronic disease (Anderson et al., 1995). It is a challenge to both the mental and physical recourses of the individual caregiver (Low et al., 1999).

Han & Haley (1999) argue that stressed caregivers can hamper the rehabilitation process of stroke survivors, as well as increase the need for long-term institutionalization. Van den Heuvel et al, (2001) focus on two theories as being associated with care giving stress. One was that the duration of care giving had an effect on stress and the other is that over time, caregivers learn to adapt to the situation.

Caring for stroke patients has been established as having a detrimental effect on social health, in which caregivers experience at least one lifestyle change (Periad & Ames, 1993). Resources such as information, assertiveness, social support, health and material resources play an important role in the caregivers' well-being (Anderson et al., 1995).

Strain can either be physical or emotional. It refers to the extent to which caregivers perceive observable negative events related to their patients' emotional or behavioral difficulties as problematic (Brannan, Heflinger & Bickman, 1997). It also refers to the unobservable emotional impact of care giving. Early discharge from hospital, the patient's level of cognition, behaviour and speech impairment increase the strain on caregivers (Bressick & Harvey, 1997).

A growing number of reports over the past decade have focused on caregiver strain following stroke. A study by Bugge, Alexander & Hagen (1999) reveals that 37% of caregivers experience considerable strain six months after stroke. In another report, one fifth of the caregivers still find themselves under strain five years after their spouse's stroke (Wilkinson, Wolfe, Warburton, Rudd, Howard, Ross-Russell and Beech, 1997). A study by Bugge et al, (1999) reveals that 37% of caregivers experience considerable strain six months after stroke.

Poor sleep quality, fatigue, pain and gastrointestinal disorders have been reported to be frequent symptoms among caregivers (Williams, 1993). There are a number of factors that explain the caregiver strain. According to Bressick & Harvey, (1997) emotional strain may be greater when the patient's cognition, behaviour and speech are impaired. Because of the rapid growth of stroke cases, there is a constraint on budget and bed places and hence to create room for other cases most of them are discharged prematurely. Early discharge (due to financial and other constraints on the health service) increases the strain on caregivers (Bressick & Harvey, 1997).

Brannan et al, (1997) examined data from the caregiver Strain Questionnaire (CGSQ), a 21-item self-report instrument that measures caregiver strain. Factor analysis showed three dimensions of strain related to both objective (observable) and subjective (felt) strain. These are (1) Objective caregiver strain, or *observable* occurrences of strain due to the family member's mental health problems; and (2) Internalized subjective caregiver strain, feelings internalized by the caregiver such as sadness, worry, and tiredness and (3) Externalized subjective caregiver strain, or negative feelings directed towards the patient such as resentment, anger, and embarrassment.

Clinical depression is a mental state characterized by feelings of sadness, hopelessness, and loss of interest experienced by most individuals (Marshal, 1996). Evidence to date clearly suggests that stroke care giving is highly stressful and leads to clinically significant depression in caregivers (Anderson et al., 1995). Han & Haley, (1999), in the articles they reviewed, found higher depression levels amongst caregivers compared to non-caregiver populations. In caregivers who did not verbalize feelings of frustration or stress, the onset of depressive symptoms signal burnout. Such caregivers experience changes in sleeping habits, appetite, and energy. Some studies have recorded high numbers (39%) of depressed caregivers (Kotila, Numminen, Waltimo and Kaste, 1998). Caregivers are more likely to become depressed if the patients are severely dependent (Dennis et al., 1998). It has also been argued that it is the behavioral changes occurring in the patient rather than the physical impairment, which contribute to the caregivers´ ill-being (Anderson et al., 1995).

If caregivers can be provided with the information and skills to reduce, or prevent, problematic behaviours, the incidence and severity of depression among caregivers could be greatly reduced (Kotila et al., 1998). The family caregiver constantly is subjected to the stress of watching a loved one's pain without being able to erase or remove it, so depression among caregivers is common, as are guilt, frustration, exhaustion, loneliness and feelings of helplessness. There is evidence that depression in stroke caregivers worsens the patients' depressive symptoms and predicts poor responses of patients to rehabilitation (Glass, Matchar, Belyea & Feussner, 1993; Scholte, Reimer, de Haan, Pijnenborg, Limburg, & van den Bos, 1998).

2.7 DISRUPTION OF DAILY ROUTINE

The various needs of stroke patients, such as help in activities of daily living, can cause disruption of the caregivers' daily routine (Eaves, 2000). Caregivers, not only deal with the patients' well-being but that of their own lives too (Bakas et al., 2002). Many end up sacrificing their social lives, friends and jobs.

Caregiving changes family roles as the patient is unable to assume his or her previous roles. Denman (1998) identifies change of family roles such as household chores, managing finances and cooking. A poor economic background worsens the situation as paying for respite care is impossible. Many caregivers and families, especially those with a good economic background, (mostly in developed countries) are ready to pay for respite care to allow themselves relief for a time (Chiu, Tang K, Shyu, & Chang, 1999).

2.8 NEGLIGENCE OF CAREGIVERS BY HEALTH PROFESSIONALS

In Bakas et al, (2002) a caregiver commented that when she took her husband to the doctor, everyone asked him how he was doing and she asked them why they were not asking how she was doing. This shows how health professionals concentrate on the needs of the patient and overlook the needs of the caregiver.

Time and again, caregivers are neglected by health professionals in practice (Low et al., 1999).

As a health resource, informal caregivers play an influential role in promoting successful rehabilitation outcome in stroke survivors (Evans, Connis, Bishop, Hendricks, & Haselkon, 1994 and Anderson et al., 1995). According to Kerr & Smith (2001) caregivers are reassured that following discharge they will receive adequate support from the health and social services, but in fact what has been provided is inadequate and they feel isolated and abandoned. Many of the caregivers after discharge are often left to teach themselves how to care for the patient and themselves (Simon & Kumar, 2002).

A factor central to the development of a successful intervention is the involvement of caregivers themselves in the process (Kerr & Smith, 2001). According to Low et al, (1999) there appears to have been few attempts to provide caregivers with the opportunity to present the consumer/user perspective and to assist in the development of services.

Failure to involve caregivers contributes to the provision of services that are inadequate, inappropriate and poorly tailored to individual needs (Brereton & Nolan, 2002; Richardson et al., 1996). According to Kerr & Smith (2001), caregivers are reassured that they will be provided with all the help they need in the community, but this does not turn out to be the case once the patients are discharged from the hospital. Health professionals assume that relatives will care for the patient, but no one has asks them whether they are able or willing to do so.

2.9 PERCEIVED NEEDS OF CAREGIVERS

The theoretical perspectives of this study, in consideration of needs of caregivers for stroke patients, are that caregivers are affected in the process of care giving as their lives are changed and that they have various unmet needs.

The body of data describing the perceived needs of caregivers of stroke patients is extremely limited (Zwygart-Stauffacher et al., 2000). Pound, Gompertz and Ebrahim (1993) statwe that their are shortcomings of stroke services in meeting caregivers' needs. These are mainly in the provision of sufficient information on issues such as allowance entitlements, post-discharge service needs, caregivers' domiciliary support and the provision of aids and adaptations (Pound et al., 1993; Van der Smagt-Duijnstee et al., 2001). Caregivers' perceptions of their own needs are necessary for professionals to identify unmet needs, organize and deliver health care that is of high quality and is client centred. It is with the use of comprehensive "need surveys" that health professionals will have, an understanding of what is needed for ideal, or at least, adequate care of stroke patients and of their caregivers (Zwygart-Stauffacher et al., 2000). Apart from socio-economic needs. Zwygart-Stauffacher et al, (2000) further identified various needs including information, emotional and spiritual needs, respect, recreation, employment, coping resources, respite services and resources. Lilley, Lincoln and Francis (2003) emphasize that follow-up is vital in the needs-led approach as caregivers are usually reluctant to ask for help as they fear being labeled as incapable. Professionals often overlook the fact that caregivers have specific problems that need to be addressed. Identification of areas of caregiver needs can be used to plan the support packages (Low et al., 1999).

2.9.1 NEED FOR INFORMATION AND KNOWLEDGE

The major need frequently identified in various pieces of literature was that of information (Van der Smagt-Duijnstee et al., 2001; Denman, 1998 Garwick, Patterson & Blum, 1995; and Thorne, 1993). In Van der Smagt-Duijnstee et al, (2001), ninety-five percent of caregivers find it very important to have information. The results also show that the amount of information provided failed to meet the caregivers' needs by a considerable margin. Several recent large-scale studies in the UK have highlighted that caregivers often experience difficulties in obtaining even basic information (Banks, 1999; Warner & wexler, 1998). An example of information lacking is on what it means to be a caregiver and the nature of illness their relative suffers (Brereton & Nolan, 2002). Caregivers are uncertain about how to obtain potentially useful information and this restricts the knowledge of what a stroke is and how to prevent recurrence, as well as restricting the stroke survivors' reintegration into daily and social activities (Lilley et al., 2003). Some caregivers resort to reading the notes in the patient's file on their own to know what exactly is wrong with him or her (Brereton & Nolan, 2002). In the midst of an illness that they have probably never heard of, information is essential to the caregivers.

The health professionals' Involvement in the family and particularly with the caregivers, as well as keeping them all informed, are important aspects in building partnerships in the rehabilitation process (Wellwood, Denis & Warlow, 1995). Information needs to be tailored to the family's situation, their comprehension, their anxiety level, and their questions and concerns. Thorne (1993) argues that while events triggering the transition, from total trust to utter disenchantment are various and individual, some common themes emerge from the accounts. One such theme is the perception that information is being withheld from the patient and family. Van der Smagt-Duijnstee et al, (2001) categorize needs into three, being the need for information, counseling (a combination of communication and support) and accessibility. In 100% of the cases they record that the most important need of caregivers of stroke patients is that their questions be answered honestly.

Patients and caregivers are anxious for knowledge in the following areas: causation of stroke and the risk of recurrence; prognosis and the rate of recovery; mental health and social isolation; services available and what they could do to help themselves (Denman, 1998 and Anderson et al., 1995). In Bakas et al, (2002) most caregivers needed better education about the signs and symptoms of stroke because they worry about future strokes and they express concern that the symptoms can be subtle or mistaken for another form of illness. Dowswell, Lawler, Dowswell, Young, Forster and Hearn (1997) state that Service users consider information and advice received from standard after-care services as inadequate. Garwick et al, (1995) express caregivers' concerns on how they are informed and the quality and size of the information they receive. They appreciate professionals who keep them informed and focus generally on the patient. Caregivers recommend that they be informed about serious issues concerning the patient in a separate room (Garwick et al., 1995). The lack of basic knowledge not only limits the caregivers to respond and help loved ones, but also instills fear in them of being unable to assist the patients when help is possible. For example, one caregiver said *"What if he has more? How are we supposed to know?... …the doctor said it would have been better if he came in [that] night. We could have stopped it."*

Caregivers, who have insufficient or no information, are detrimental to the advancement and progress of therapeutic intervention, largely because they, who spend the most time with the patient, are not coherent with the treatment goals. Family caregivers need information, not only about how to care for the stroke survivor in the home setting, but also about how to care for themselves (Bakas et al., 2002).

2.9.2 COMMUNICATION

Communication is a vital tool in ensuring that rehabilitation is of continuous and systematic form. Good communication between health personnel and the caregiver is very important to both parties. Health professionals have information that the caregivers do not have direct access to, even though such information concerns the rehabilitation process that has to be followed when the patient is at home. Unfortunately, in general practice, communication with the caregiver is valued only when conducting assessments and during re-assessments. In the process, various needs of the caregiver are overlooked and not addressed. The caregiver needs information in helping the stroke patient in various activities. The implications for satisfactory practice are that there is a need for professionals to find ways of recognizing and taking account of the possible tensions between their goals and those of patients and families, and related to this, for the development of strategies which enable professionals to explain clearly the nature of stroke to patients and their caregivers (Hart, 1998).

Caregivers face various problems many of which can be addressed if the professional is reachable or approachable. Many times, communication between the two is limited. Bakas et al, (2002) mention how one of the caregivers interviewed, realized she had problems, but was not able to say what she wanted to say and this led to her being frustrated.

Wellwood et al, (1995) cite communication as one of the major areas causing pitfalls in stroke rehabilitation. Pressures in the health care system in terms of poor funding and limited resources have forced the interaction between the health professional and the client to be limited (Kautzmann, 1993). Good communication between the professionals and the caregivers is a vital tool in ensuring that rehabilitation is of better quality. It appears that careful listening is the key to appropriate support and information giving (Garwick et al., 1995). Clinicians could have the most influence on family caregivers' reactions to news by planning the situation in which the caregiver is informed, assessing pre-existing factors that commonly determine caregivers' reactions, and selecting the information and emotional support strategies that met the needs of the particular caregiver (Garwick et al., 1995).

2.9.3 SUPPORT

Given the high incidence of stroke, the increasing number of family members who are becoming caregivers for the victims of stroke, and a rapidly aging population at risk of stroke, assisting caregivers is a significant priority (DeLaune & Brown, 2001). Health services are often the first point of contact for many stroke caregivers and so have the potential role in maintaining caregivers' quality of life (Low et al., 1999). A research focus on the structure and process of professional support as perceived by caregivers is important to the development and provision of stroke services. By identifying the views of service users and the process by which support impacts on caregivers, it may highlight justification for an introduction of caregiver-centred services. Lilley et al, (2003) find the need for practical support to outweigh the need for emotional support. Nevertheless, caregivers express the fact that they feel safe knowing that there was someone they can reach out to if they feel overburdened or depressed.

There is need for a skillful and flexible service for both stroke patients and their caregivers as it draws attention to the many facets of recovery and adjustment and the need for sensitivity and skill in identifying and responding to particular needs at the appropriate time (Dowswell et al., 2000). What caregivers feel about the services at their disposal is very important to the health professionals as it determines whether they will make use of the services or not. A comprehensive management of stroke patients depends largely on the cooperation of the caregiver and his or her ability to carry the burden. In the planning and implementation of services for caregivers in the community. Denman (1998) recommends that professionals should use methods to improve the situation for caregivers based on the caregivers' self-identified needs.

In order for the health planners and professionals to develop an overall understanding of health-care needs, and to be responsive, the views of caregivers about the patterns and delivery of health services ought to be taken into consideration (Kerr & Smith, 2001).

Stroke caregivers play an important supporting role in the rehabilitation process, a role which may increase with a growing trend of providing stroke rehabilitation in survivors' own home once they have been discharged from hospital (Low et al., 1999).

There are various support services that caregivers require. Low et al, (1999) reveal that several caregivers are deeply concerned about having inadequate finances to support the stroke survivor in the home setting. McLean et al, (1991) reported that caregivers feel inadequately supported by stroke services in tackling their emotional and personal problems, in particularly, when dealing with both the lifestyle and role changes caused by the onset of a severe stroke. Physiotherapists are in a position to ensure that caregivers of stroke patients are supported after discharge as they have greater interaction with them than any other health professional before and after discharge.

2.9.4 REHABILITATION SERVICES

In Brereton & Nolan (2002), caregivers comment on how busy the staff of hospitals and clinics is and how this often means that patients are waiting for care, particularly assistance to use toilet facilities. Numerous caregivers, though not having the professional 'know how' show concern about the quality of care that their relative receives. Many developing countries have limited resources such as personnel, medical and rehabilitation facilities. This may be a major disadvantage in providing quality services to caregivers. The satisfaction of caregivers is pertinent to how much benefit is obtained from provision of these services, and ultimately, should increase the cost effectiveness of the service (Bugge et al., 1999).

2.10 FACTORS INFLUENCING CAREGIVERS' NEEDS AND EXPERIENCES

One of the most influential theories of health-related behaviour, the health belief model postulates that the peoples' behaviour in relation to health is related to their perceptions of the severity of an illness, their susceptibility to it and the costs and benefits incurred in following a particular course of action (Bowling, 2000).

Many studies report that the patient's condition has an influence on the caregivers' experiences and needs (DeLaune & Brown 2001; Han & Haley, 1999; McNamara, Gummow, Goka & Gregg, 1990). Dennis et al, (1998) confirm that caregivers of more severely disabled patients had more distress, although interestingly, their level of anxiety does not seem to be related to the patients' level of dependency. Contrary to the expectations, Wellwood et al, (1995) found that caregivers of patients who had perhaps the worst outcome seemed most satisfied. In other studies, the physical disability of stroke patients, measured by the Barthel Index (BI), was not related to caregivers' depression (Kotila et al., 1998; Anderson et al., 1995; Draper, Poulos, Cole, Poulos & Ehrlich, 1992 and McNamara et al., 1990).

Bugge et al, (1999) find that the amount of time a caregiver spends helping a stroke patient and the caregiver's health determine the level of strain. Gaynor (1990) also suggests that years of persistent physical and emotional work associated with caring for a family member with a chronic illness can increase a perceived sense of burden. According to Van den Heuval (2001) and Draper et al, (1992) the duration of the care-giving role does not have any effect on caregivers' strain or well-being. It is concluded that people who have recently become caregivers experience similar levels of strain to those who have been looking after a relative for a longer time.

A study by Teel et al, (2001) examines care giving within the context of change, between the first and the sixth month after a loved one's stroke. One would expect different results at different periods of time as the patient is making progress. Unexpectedly, caregivers reported consistent perceptions of fatigue, vigour, recurrent sorrow, perceived stress, difficulties with finances, unavailability of family support, perceived physical health, and the presence of depressive symptoms at 1,3 and 6 months after the loved one's stroke. In all, 54% of patients feel at least mildly depressive at some time during the follow-up; 46% of those who are depressive during the first 2 months are also depressive at 12 and/or 18 months (Berg, Palomäki, Lehtihalmes, Lönnqvist, & Kaste, 2003).

Bressick & Harvey (1997), as well as Dennis et al, (1998) state that early discharge, the patient's cognition, behaviour and speech impairments and level of disability to be factors that increase the strain on caregivers. This is as a result of caregivers having insufficient knowledge, exposure to observing the rehabilitation process, and contact with the rehabilitation workers. It is assumed that discharging a patient only when they have attained a higher level of function may decrease strain in caregivers.

In contrast, another study identifies factors influencing the experience of caregivers to be related to whether the caregiver lives with the patient and the quality of the caregiver's relationship with the patient before the stroke, rather than to characteristics of the stroke (Anderson et al., 1992). Purk and Richardson (1994) find that the closeness of the caregiver's relationship with the stroke survivor plays an important role in maintaining caregiver's psychological well-being. Those closely related had poorer psychological health than those distantly related

More empowered caregivers (the degree to which they expressed a sense of competence and confidence in their ability to deal with problems), report less stress and more enrichment (Yatchmenoff, Koren, Friesen, Gordon, & Kinney, 1998).

According to Bugge et al, (1999) caregivers' characteristics are most closely related to caregiver strain, mood and the caregivers' perceptions of their partner's ability in activities of daily living. In Van der Smagt-Duijnstee et al, (2001) results showed that the need for information and counseling are influenced by gender as female caregivers attach greater importance to this need than male caregivers.

The severity of the consequences of the disease in some studies is reported to increase the level of stress (Gallagher-Tompson, 1997; Kelly-Hayes, 1990). Stroke patients, who are at different time periods after stroke generally have different severity and manifestation of neurological deficits, and different levels of functional impairments and depression status (Spencer, Tompkins, & Schulz, 1997 & Kelly-Hayes, 1990). Hodgson, Wood & Langton-Hewer (1996) maintain that the physical health of caregivers is one of the predictors of caregiver's well being.

There is no doubt that disability has an impact on families who have a disabled member. Families bear all of the cost of treatment of their disabled family member, and these costs often include transportation, appliances and/or equipment (Mitchell, 1999). Care giving may be a burden financially, depending on factors such as, the caregiver's employment status, the patient's employment status and other people related to the patient who may offer some financial assistance. Anderson et al, (1995) find that the economic issue becomes a problem and is most relevant to caregivers when the main wage-earner at their home has experienced the stroke and also when the children supported a disabled parent.

2.11 SUMMARY

In this chapter, the needs and experiences of caregivers are reviewed. stroke was idefined and the role of the caregiver explained. The impact of care giving on caregivers is highlighted. Other issues discussed are, neglect of caregivers by professionals, the socio-demographic characteristics of caregivers, health status of caregivers, caregivers' needs and experiences and factors influencing them.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 INTRODUCTION

In this chapter, the research setting, research subjects and sampling, instruments used, procedure, data analysis and ethical considerations will be described.

3.2 RESEARCH SETTING

The study was carried out at the University Teaching Hospital (UTH) in the central constituency of Lusaka the capital city of Zambia. Zambia is located in the southern region of Africa. It is a landlocked country surrounded by 8 countries namely, Malawi, Tanzania, Democratic Republic of Congo, Angola, Namibia, Mozambique, Botswana and Zimbabwe. It is administratively divided into nine provinces. The population of Zambia is 10.2 million and Lusaka, the capital city, has a population of approximately 1.3 million (Central Statistics Office, 2001).

Primary health care forms the basis of the countries health system, with health services being provided at tertiary and secondary hospitals, community health centers and clinics.

The University Teaching Hospital is the largest tertiary hospital in the country. It is owned by the government and operates both as a central and university hospital with over 2000 beds. It is the largest provider of a full range of primary, secondary and tertiary health care services on an in-patient and outpatient basis in the country and serves as the primary referral hospital for the rest of the country.

The hospital provides a variety of services on an out-patient and in-patient basis. The facilities include medical wards, surgical wards, orthopaedic wards, obstetrics and gynaecology wards, paediatric wings, Intensive Care Unit (ICU), four pharmacies, radiography, physiotherapy, social work and an orthopaedic workshop.

Physiotherapy services are provided by twenty full time physiotherapists as well as students from Evelyn Hone College and the University of Zambia who attend practical sessions at the institution as part of their academic requirement. At the time of data collection nine physiotherapists were on study leave engaging in the newly introduced degree programme at the University of Zambia.

The physiotherapy department provides in-patient and out-patient services to clients with a variety of diagnoses, which include sports injuries, post trauma injuries, neurological disorders and arthritis. A large number of patients who have suffered a stroke are treated at the out-patient physiotherapy department each day. Of the 80 patients with various diagnoses who are treated at the department daily, an average of 30 of these are patients who have suffered a stroke.

3.3 STUDY DESIGN

A cross-sectional descriptive study design utilizing a questionnaire with closed-ended items and another with open-ended items administered by the researcher are used in the present study. The methods employed in the present study attempt to gain a broader understanding of the needs and experiences of informal caregivers. The inclusion of open ended items further captured information on a wide range of support services needed by caregivers including provision of information to caregivers which could not be captured using closed ended questions (Harding & Lincoln, 2000; Bless & Higson-Smith, 2000).

3.4 RESEARCH POPULATION AND SAMPLING

All the primary caregivers of stroke patients dependent in at least one ADL and attending the out-patient physiotherapy department at UTH during the period that data collection took place were identified and recruited to participate in the study. The final study sample consisted of 70 caregivers. Purposive sampling was employed to choose 10 subjects out of the 70 to be interviewed using an interview guide. Purposive sampling is selective in nature as the researcher selects according to specific data that he needs from the sample (Harding & Lincoln, 2000). The criteria used to select the 10 subjects were socio-demographic variables namely age, gender, living arrangements, economical and educational status.

3.5 METHODS OF DATA COLLECTION AND INSTRUMENTATION

Interviewing is one of the most common and powerful ways in which we try to understand our fellow human beings and comes in a variety of forms and is used for different purposes. The most common form of this universal mode of systematic enquiry involves individual, face-to-face verbal interchange, but interviewing can also take other forms for example telephonically (Denzin & Lincoln, 2000). This study used the face-to-face method of interviewing for collection of the questionnaire data. The research through interviews may obtain a great deal of information such as the following (Silverman, 1993):

- Facts (e.g., biographical information)
- People's beliefs about the facts
- Feelings
- Motives
- Present and past behaviours
- Standards for behaviour (i.e., what people think should be done in certain situations)
- Conscious reasons for actions or feelings

The face-to-face method is the most appropriate technique that could be employed for the researcher to take into consideration the personal, social, cultural and spiritual contexts of the interviewees (Fontana & Frey, 1994). Face-to-face interviews involve direct personal contact with the participant who is asked to answer questions related to the research problem. The use of interviews to acquire information is so extensive today that it has been said that we live in an "interview society" (Atkinson & Silverman, 1997; Silverman, 1993).

One questionnaire consisted of closed-ended questions while the other consisted of open-ended questions. The questionnaires had an established set of questions with fixed wording and sequence of presentation, as well as more or less precise indications of how to answer each question (Bless & Higson-Smith, 2000).

Open-ended questions offer the respondents complete freedom to express their answers as they wish, as detailed and complex, as long or as short as they feel appropriate. No restrictions, guidelines, or suggestions for solutions were given. Open-ended questions provide the researcher with a greater breadth of data because of their character.

All the questionnaires where administered by the researcher in the form of interviews. The use of researcher-administered interviews has advantages and disadvantages. Bless & Higson-Smith (2000) argue that the advantages of a questionnaire administered by the interviewer are that they can be used on people who cannot read or write, poor sectors of the population and young children especially those in developing countries. It was surely an advantage in this study as some of the respondents were unable to read. Face-to-face interviews are also instrumental in overcoming misunderstandings and misinterpretations of words or questions (Bless & Higson-Smith, 2000). Furthermore once in doubt the interviewee was able to seek clarity without any difficulties. According to some researchers, the presence of an interviewer can be perceived as a handicap as far as anonymity and respect for the private life of the respondent is concerned (Bless & Higson-Smith, 2000; Denzin & Lincoln, 2000).

3.5.1 INSTRUMENTATION FOR DATA COLLECTION USING THE CLOSED ENDED ITEM QUESTIONNAIRE

An interview questionnaire (Appendices I, II, III and IV) used to collect data in this study, was adapted by the researcher from validated scales from literature to gather socio-demographic information of caregivers and patients (Wyller, Thommessen, Sondring, Sveen, Petersenj, Bautz-Holter & Laake, 2003; Montgomery, Borgatta & Borgatta, 2000). Other scales included in the questionnaire were the caregiver's Health and Well-being Questionnaire, the 5-item Bartel Index, the Caregiver Strain Index (SCI) and the Family Care giving Scale (Appendices I, II, III and IV).

The section requested information relating to the caregivers' and patients' socio-demographic data namely, the age, gender, home language, marital status, education level, employment status, income, living arrangement, relationship between the caregiver and the patient and information regarding the patients' date of discharge and date of the stroke attack.

The section on the caregiver's health and well-being is adapted from questionnaires used by Wyller et al, (2003) and Montgomery et al, (2000) and comprises information relating to the informal caregiver's health. Information relating to the general health of the informal caregivers was collected using three questions. One question asked the caregivers self-perceived health status and has five choices for answers ranging from very poor to very good. The second question refers to the number of diseases or symptoms the caregiver has reported on a checklist. The total number of those identified by the caregiver was noted. The last question is on any other diseases or symptoms the caregiver has reported which are not mentioned in the checklist (see Appendix I).

3.5.1.1 THE 5-ITEM BARTHEL INDEX

The number of activities of daily living (ADLs) the patient needed assistance with according to the caregiver's perception was recorded on the 5-item Barthel Index (Appendix I). The 5-item Barthel index (BI-5) was validated with an alpha coefficiency of > 0.71 (Hsueh, Lin, Jeng & Hsieh, 2002). The modified scale comprises 5 activities of daily living. The maximum score is 5 points, representing independence in daily living and the mnimum score is 0, indicating total dependency in activities of daily living. The items on the scale are bathing, feeding, mobility, toileting and dressing. Scoring is according to the number of items the patient needs assistance with.

3.5.1.2 THE FAMILY CAREGIVING SCALE

The family care giving scale is a Likert scale developed by Montgomery et al, (2000). It contains four subscales namely, the family demand burden, stress burden, family objective burden and family involvement in care plan (see Appendix IV. The internal consistency of all the subscales was measured by Cronbach's Alpha in previous studies and the alpha level was high, indicating good internal consistency.

Subjective demand burden is defined as the extent to which the caregiver perceives care responsibilities to be overly demanding (Montgomery et al., 2000). The demand burden subscale measures the level of demands made by the patient that could be burdensome to the caregiver using four variables. These variables are; increased attempts by the patient to manipulate the caregiver, increased numbers of unreasonable requests made by the patient, increased feeling by the caregiver of being taken advantage of and increase in demands made by the patient. The scores for items range from 1 = a lot less to 5 = a lot more. The total scores of the subscale range from 4 to 20. A score of more than 10 indicates an increased level of burden due to demands made by the patient. According to Montgomery et al, (2000), the reliability (Cronbach's alpha) has ranged from 0.81 to 0.88 in previous studies with mean scores of large samples of caregivers ranging between 12.6 (standard deviation = 2.4) and 12.7 (standard deviation = 2.0). Cronbach's alpha measures how well a set of items (or variables) measures a single one-dimensional latent construct.

Subjective stress burden is the emotional impact of care giving responsibilities on the caregiver. It has four items that include stress in the relationship with the dependent relative, tension in the caregivers' life, nervousness and depression related to the relationship with the dependent relative and anxiety about things. The scores for items range from 1= a lot less to 5 = a lot more. Total scores range from 4 to 20. Montgomery et al, (2000) states that previous research indicates mean scores for a wide range of caregiver samples ranging between 13.2 (standard deviation = 3.3) and 13.6 (standard deviation = 2.9). Based on this information scores above 13.5 could be viewed as quite high. The higher the scoring, the higher the stress level. According to Montgomery et al, (2000) the reliability (Cronbach's alpha) on previous studies ranged from 0.81 to 0.89 indicating very high stress levels among caregivers.

The objective burden subscale measures the burden of caring for the stroke patient. It has six items and focuses on how caring objectively affects the caregiver especially its confining nature. These items are; decrease in time the caregivers have for themselves, restriction in caregivers' personal privacy, decrease in time for recreational activities, restriction in vacation and trips taken by the caregiver, less time spent by the caregiver on own work and chores and less time spent by the caregiver with friends and other relatives. Scores on this subscale are in reverse form, where five is equal to a lot less and one is equal to a lot more. According to Montgomery et al, (2000) the reliability (Cronbach's alpha) on previous studies ranged from 0.88 to 0.91. The family objective burden subscale scores range from 6 to 30 and a point value of over 15 can be viewed as quite high.

The family involvement in care plan subscale is used to collect information concerning the health professional's involvement of a caregiver in the patient's care plan. It contains four variables on how often the caregiver cares for the patient, the number of visits to the physiotherapy department, how often the caregiver discusses with physiotherapy staff about the patient and how much the caregiver helps with assistance with grooming the patient per month. This scale has been validated and according to Montgomery et al, (2000) the reliability (Cronbach's alpha) on previous studies ranged from (.68 to .77). The subscale total scores range from 4 to 20. A record of less than 12 indicates that there was less involvement of the caregiver in the care plan of the past month.

3.5.1.3 REHABILITATION AND SUPPORT SCALE

The Rehabilitation and Support Scale addresses the caregiver's perception of rehabilitation and support through five questions. The questions concern the effects of intervention considered important by caregivers, rating of information received and supported provided by physiotherapists, rating of the caregivers' satisfaction with physiotherapy and rehabilitation services, attention received by caregivers from physiotherapists during follow-up and the caregivers' perception on the importance of the need of support workers for stroke survivors in the community.

3.5.1.4 CAREGIVER STRAIN INDEX (CSI)

The caregiver Strain Index (CSI) is an ordinal scale, used to identify families with potential care-giving strain. It is a 13-question tool that measures strain related to care provision in providing various degrees of care to patients at home. Each item is answered with a "yes" or "no" response. Scoring is accomplished through adding all affirmative responses to arrive at a total score; thus, a higher score implies a higher level of burden (Scherbring, 2002). There is at least one item for each of the following major domains: Employment, Financial, Physical, Social and Time (see Appendix II). Positive responses to seven or more items on the index indicate a greater level of strain. This instrument can be used to assess individuals of any age who have assumed the role of caregiver of chronically ill patients (Thornton & Travis, 2003: Stewart & Neyerlin, 2000 and Bugge, et al., 1999). According to Blake & Lincoln (2000) internal consistency reliability is high (alpha=0.86).

3.6 INSTRUMENTATION FOR COLLECTION OF DATA FROM THE QUESTIONNAIRE WITH OPEN ITEMS

An eight-item questionnaire was developed from literature specifically for data collection from open-ended items. It contains seven open-ended questions on the needs and experiences of caregivers (see Appendix V). The open-ended questions form the basis of the interview guideline and thus never pre-determined the responses, or limited the responses of the caregivers.

The eight-item interview guide had open-ended questions concerning the caregivers typical day, the early days post discharge, their experiences, concerns, needs, perceptions of rehabilitation intervention, information and communication and any other issues they wished to discuss. The researcher administered all the interviews.

To ensure that the interviews were credible and trustworthy, the researcher recorded the interviews and took field notes. The researcher also ensured that the respondents understood the questions very well. If they were not sure, the questions were repeated.

3.7 PROCEDURE

The study was conducted at the University Teaching Hospital in Lusaka, Zambia. Following ethical clearance from the Ethics committee at the University of Zambia, a local transcriber was engaged to translate independently the English version of the questionnaires to Nyanja (a local language) and a second transcriber translated it back to English to ensure reliability. The copies had a few differences. For example, the initial transcriber had interpreted 'relationship to dependant' in the Socio-demographic section of the questionnaire with closed-ended items as 'friendship to dependant.' The differences were noted and corrected. Both of the transcribers and the researcher were involved in this process.

3.7.1 PILOT STUDY

A pilot study was conducted at Chainama Hills Hospital in order to familiarize the researcher with the administration of the questionnaires and to check for the subjects' understanding of questions.

Participation by the caregivers of stroke patients attending physiotherapy sessions was on a voluntary basis. The nature of the study was explained to them and then a written consent obtained. A total of four caregivers were interviewed. Following the pilot study, three changes were made to the questionnaires. It was noted that some questions were repetitions and thus were omitted from the final copies of the questionnaire. The questions that were repeated were concerning the need for respite care, financial burden of care giving and experiencing of stress.

3.7.2 DATA COLLECTION

Data collection took place from 14th July 2003 to 7th August 2003. The chief physiotherapist at UTH introduced the researcher and explained the research to the departmental staff. Physiotherapists attending to the patients identified the caregivers of stroke patients needing assistance with Activities of Daily Living and referred them to the researcher after informing them about the nature of the study. Those willing to participate were requested to sign a written consent form and were informed that they were free to withdraw from participating in the study at any point. They were assured of anonymity and confidentiality.

The questionnaire with closed-ended items was administered to the caregivers by the researcher when they brought the patients for out-patient treatment at the department of physiotherapy. Approximately six interviews were conducted per day and lasted between 30 to 45 minutes. Collection of data from the questionnaire with closed-ended items took place between 14th July 2003 and 31st July 2003 and a total of 70 caregivers were interviewed.

Ten caregivers were selected purposively from the 70 caregivers and interviewed using the face-to-face method between 1st August 2003 and 7th August 2003. They represented diverse characteristics that the caregivers had such as age, gender, employment status and relationship to the patient. All the questionnaires were written in both English and Nyanja (the local language in Lusaka).

In-depth interviews were conducted with the caregivers at the hospital or in the caregivers' home. The rooms where the interviews were conducted were assessed prior to commencing the interviews to check the recording machine sound. The interviews took approximately one to one and a half hours. An average of two interviews were conducted per day.

3.8 DATA ANALYSIS

3.8.1 ANALYSIS OF DATA CAPTURED FROM THE CLOSED-ENDED QUESTIONNAIRE

Descriptive and inferential statistics were employed in analyzing data from the closed-ended questionnaire. The Word Excel computer programme was used to code and capture the data on a spreadsheet. The Statistical Package for Social Sciences (SPSS) was used in order to obtain frequencies, cross tabulations and correlations. Some properties of the sample results, such as demographic status e.g. gender and age, economic and health status, were inferred with the caregivers' needs and experiences such as strain, health and need of respite care using Pearson's and spearman's correlation co-efficiency with significance at the 0.01 and 0.05 level (2-tailed). The Excel programme was used to process and summarize data into tables and figures.

3.8.2 ANALYSIS OF DATA CAPTURED FROM THE OPEN-ENDED QUESTIONNAIRE

The audio taped interviews were transcribed *verbatim*. Each interview was read several times and coded. The data was reduced into categories and categories into themes.

3.9 ETHICAL CONSIDERATION

Ethical clearance was first obtained from the Higher Degrees Committee of the University of the Western Cape's Faculty of Community Health Sciences. Permission was sort from the Head of the Physiotherapy Department at UTH to conduct the study. The head of the Physiotherapy Department at Chainama Hills Hospital was contacted to seek permission to conduct the pilot study. In addition the researcher was referred to the Ethics committee of the University of Zambia for ethical clearance.

Physiotherapists (i.e. the physiotherapist who regularly sees the patient) asked the caregivers for permission to be involved in the study. Willing caregivers were seen by the principal investigator and informed consent was obtained. They were assured of confidentiality and informed of their right to withdraw from the study at any stage. Information obtained was handled with the greatest confidentiality. A summary of the study will be made available to the informal caregivers, heads of the institution and the therapists treating the patients.

CHAPTER 4

RESULTS

4.1 INTRODUCTION

This chapter deals with the analysis, interpretation discussion of data obtained through the closed-ended questionnaire which will be presented under the following major headings; socio-demographic distribution of caregivers and patients, duration of care giving, Activities of Daily Living (ADLs), experiences of care giving, needs of caregivers and factors that influence the caregivers' needs and experiences.

Data captured from the open-ended questionnaire will be presented in chapter 5 with the disussion of the results. The themes that were more frequent were information relating to stroke rehabilitation and knowledge about stroke, discontinuity of caregivers' daily routine, need for support services, work overload, need for community centred programmes, need for finances, views on physiotherapy rehabilitation services, and need for respite care.

4.2 SOCIO-DEMOGRAPHIC DATA

The mean age of the study population was 37.6 years, with ages ranging from 16 years to 85 years and a standard deviation of 16.5 years. The study sample consisted of more females (70%) than males (30%).

Table 4.1 illustrates the gender distribution according to the different age ranges. In the present study 93% of the respondents were younger than 60 years and the highest percentage of caregivers being between 15 and 30 years old (43%).

Table 4.1 Age and gender of caregivers

Age Group Interval	Total		Male		Female	
	N = 70	(%)	N=21	(%)	N=49	(%)
15-30	30	42.9	10	(14.3)	20	(28.6)
31-45	21	30.1	8	(11.5)	13	(18.6)
46-60	14	20	1	(1.4)	13	(18.6)
61-75	3	4.2	2	(2.8)	1	(1.4)
76-90	2	2.8	0	(0)	2	(2.8)

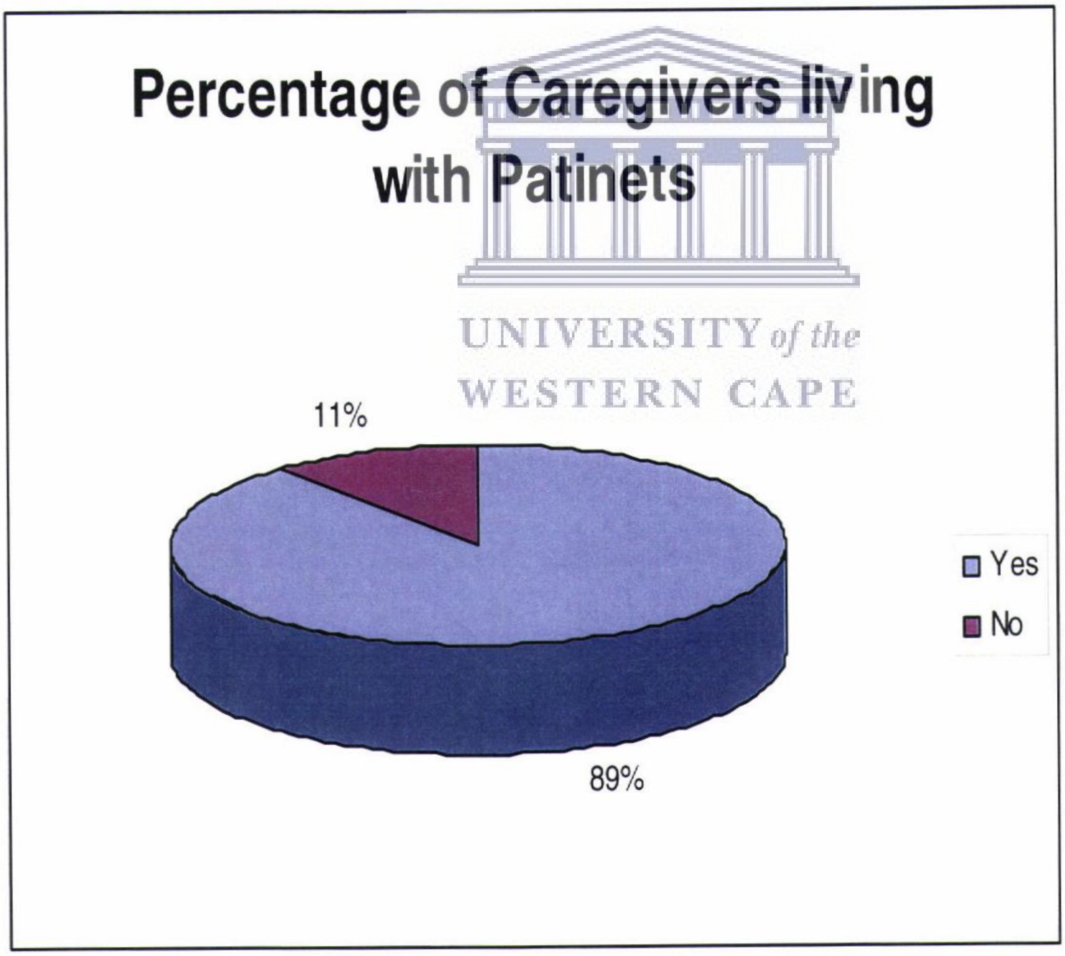
Table 4.2 illustrates the relationship of the caregiver to the patient by gender. Children of patients had the highest frequency (31%), among which females, were twice as many as males.

Table 4.2 Gender and relationship of caregiver to patient

	Child	Spouse	Sibling	Friend	Parent	Grandchild	Total
Female	15	10	9	6	5	4	49
Male	7	6	4	2	2	0	21
Total	**22**	**16**	**13**	**8**	**7**	**4**	**70**

Figure 4.1 shows that the majority of the caregivers (89%) lived in the same household as the patient. The 11% who came to care for the patient included, married daughters, sisters and other distant family members.

Figure 4.1 Living Arrangements of caregivers and the patients being cared for.



Illustrated in Table 4.3 are the employment status, educational status and the monthly income level of caregivers. The majority of caregivers had a low education level. Those that neither reached grade 12 nor went to school accounted for 60% of the population. Only 21.4% of the caregivers had obtained a college education.

The results of the present study revealed that the majority (77%) of the caregivers were unemployed and having no income at all during the time of data collection. A total of 23% had to care for their patients while having a full time job.

Table 4.3 Educational status, employment status and income level of caregiver (N=70)

Variable	N	%
Education Level		
College (tertiary level)	15	21.4
Grade 8-12	13	18.6
Grade 5-7	4	5.7
Grade 1-4	35	50
Never been to school	3	4.3
Employment Status		
Employed	16	23
Unemployed	54	77
Income Level		
Above 450K*	3	4.5
350-less than 450K	2	2.8
250-less than 350K	4	5.7
Below 250K	7	10
No income	54	77

*K = 1000. All figures are in Zambian kwacha

Note at the time of data collection, 1 South African Rand was equal to 750 Zambian Kwacha (SAR 1 = ZK 750.00).

Socio-demographic data of caregivers interviewed using the open-ended item questionnaire

Among the 10 informal caregivers interviewed using an open-ended questionnaire, the minimum age was 16 and the maximum was 86 years old with a standard deviation of 22. The mean age was 34.1 years.

There were six female and four male caregivers. The majority of them (80%) lived with the patient. The two caregivers who were employed included a brother and a husband. A total of 40% reported that they perceived their health status to be poor (Table 4.4).

Table 4.4 Socio-demographic data of caregivers interviewed using the open-ended item questionnaire (N=10)

Variable	N=10	%	Mean	Range
Age			34.1 ± 22	16-86
Relation				
Wife	3	30		
Daughter	1	10		
Mother	1	10		
Sister	1	10		
Husband	1	10		
Brother	1	10		
Son	2	20		
Living Arrangement				
Living with patient	8	80		
Not living with patient	2	20		
Employed				
Yes	2	20		
No	8	80		
Health Status				
Very poor	2	20		
Poor	4	40		
Not sure	1	10		
Good	2	20		
Very good	1	10		

4.3 CAREGIVER SELF RATING OF HEALTH STATUS

The results for the above-mentioned variable are presented in Table 4.5. The majority (81.4%) of caregivers recorded better health status and most of them expressed having a low number of illnesses (0 to 4 illnesses). Caregivers that expressed that they had poor and very poor health status had more illnesses (5-16 illnesses). A total of 23 caregivers expressed having no illnesses at all.

Table 4.5 Caregiver Self-Rated Health Status

	Frequency	%	Number of Illnesses and Medical Problems	
			0 – 4	5 - 16
Very Poor	1	(1.4)	0	1
Poor	9	(12.9)	3	6
Not Sure	3	(4.3)	2	1
Good	38	(54.3)	30	8
Very Good	19	(27.1)	17	2
Total	**70**	**(100)**	**52**	**18**

4.4 DURATION OF CAREGIVING

Table 4.6 shows that by the time the data were collected 65.8% of the patients had been attended to by the caregivers 6 months and less. Only 25.7% of the caregivers had been caring for the patients for a year and over.

Table 4.6 Duration of care giving (N=70)

Weeks	Frequency	Percent	Cumulative Percent
0 – 4 weeks	24	34.4	34.4
1 - 6 months	22	31.4	65.8
7 – 12 months	6	8.5	74.3
Over 1 year	18	25.7	100
Total	**70**	**100**	

4.5 SOCIO-DEMOGRAPHIC DATA OF PATIENTS

The mean age of the patients cared for by the respondents was 47 years, with ages ranging from 18 years to 85 years and a standard deviation of 16 years. There were more female (57.1%) than male (42.9%) patients.

Table 4.7 illustrates the gender distribution of patients according to the different age ranges. The findings of this study showed that 67.1% of the patients were 60 years and younger with the highest percentage of patients being between 46 years and 60 years old.

Table 4.7 Age and gender of patients (N=70)

Age Group Interval	Male N=30 (%)	Female N=40 (%)
15-30	2 (2.9)	8 (11.4)
31-45	8 (11.4)	8 (11.4)
46-60	7 (10)	14 (20)
61-75	9 (12.8)	10 (14.3)
76-90	4 (5.7)	0 (0)

Table 4.8 illustrates that the majority of the patients were married (55.7%), followed by those that were widowed (27.1%). The majority of patients were unemployed (71.4%) compared to those employed (28.6%). Most (n=39) of the patients were married, yet only 16 were being cared for by their spouses.

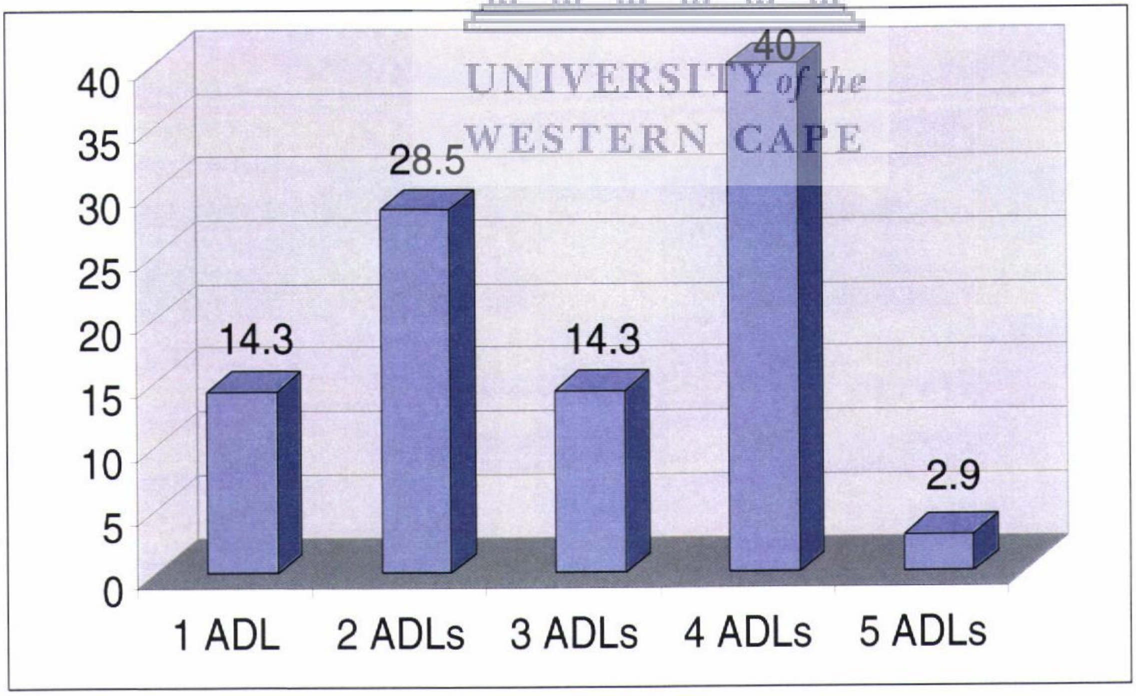
Table 4.8 Marital and employment status of patients

Variable	N	%
Marital Status		
Single	7	10
Married	39	55.7
Divorced	5	7.1
Widowed	19	27.1
Current Employment Status		
Employed	20	28.6
Unemployed	50	71.4

4.6 ACTIVITIES OF DAILY LIVING

The patients' level of dependency were recorded and measured according to the number of activities of daily living (ADLs) they needed assistance with performing according to the caregivers' perception as illustrated in Figure 4.2. Among the caregivers, 57.2% reported that their patients were dependant in more than 2 ADLs. The ADLs listed were bathing, feeding, mobility, toileting and dressing. A total of 52 (75.4%) patients were dependant in bathing, 48 (69.6%) in dressing, 31 (45%) in toileting, 23 (33.4%) in feeding and 22 (32%) in mobility.

Figure 4.2 Percentage of the number of listed activities the patient needs assistance with.



4.7 EXPERIENCES OF CAREGIVERS WITH PHYSIOTHERAPY SERVICES

Experiences that were discussed were those of caregivers' satisfaction with physiotherapy rehabilitation services, support received from physiotherapy staff, information received, involvement of caregivers in care plan by physiotherapists, impact of care giving on daily routine and work overload of caregivers as measured by the Family caregiver scale and the Rehabilitation and Support Scales.

Data collected from the closed-ended questionnaire reveal that experiences with physiotherapy intervention at the hospital were both positive and negative. Table 4.9 shows that 58.6% of the caregivers were very satisfied and moderately satisfied with the rehabilitation services offered to them.

Table 4.9 Satisfaction with physiotherapy rehabilitation services (N=70)

Rating	Frequency	Percentage
Very satisfied	14	20
Moderately satisfied	27	38.6
Slightly satisfied	18	25.7
Not satisfied at all	11	15.7
Total	**70**	**100.0**

Figure 4.3 illustrates responses of caregivers of how much attention they received from physiotherapists in regard to their needs or concerns. Caregivers viewed attention as the act of showing concern for the caregivers. It was alarming to note that of the 70 caregivers, 40 (57.2%) responded not receiving any attention from physiotherapists.

Figure 4.3. **Attention received by the caregiver from the physiotherapists (N=70).**

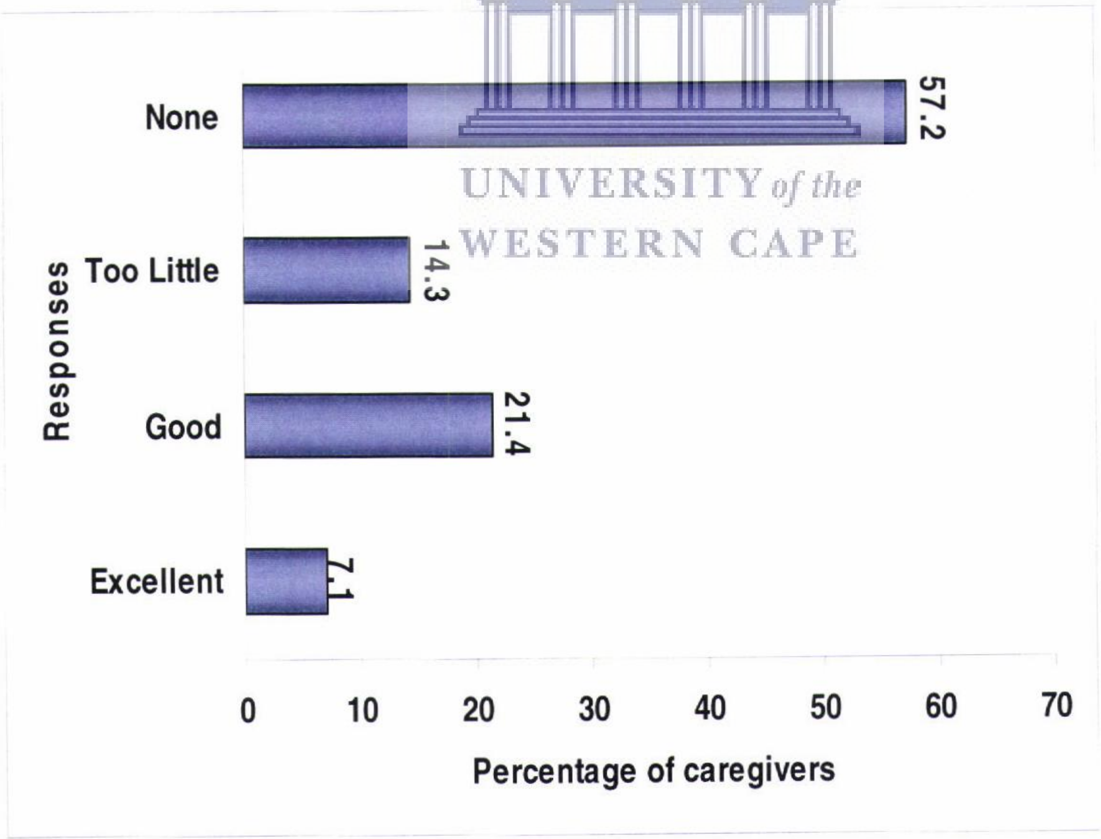


Figure 4.4 refers to the rating of information received from physiotherapists. The majority of caregivers (48.3%) expressed that they were neither provided with information nor support at all, followed by 25% who expressed that the information and support was good.

Figure 4.4 Information and support provided by the Physiotherapist to the caregiver

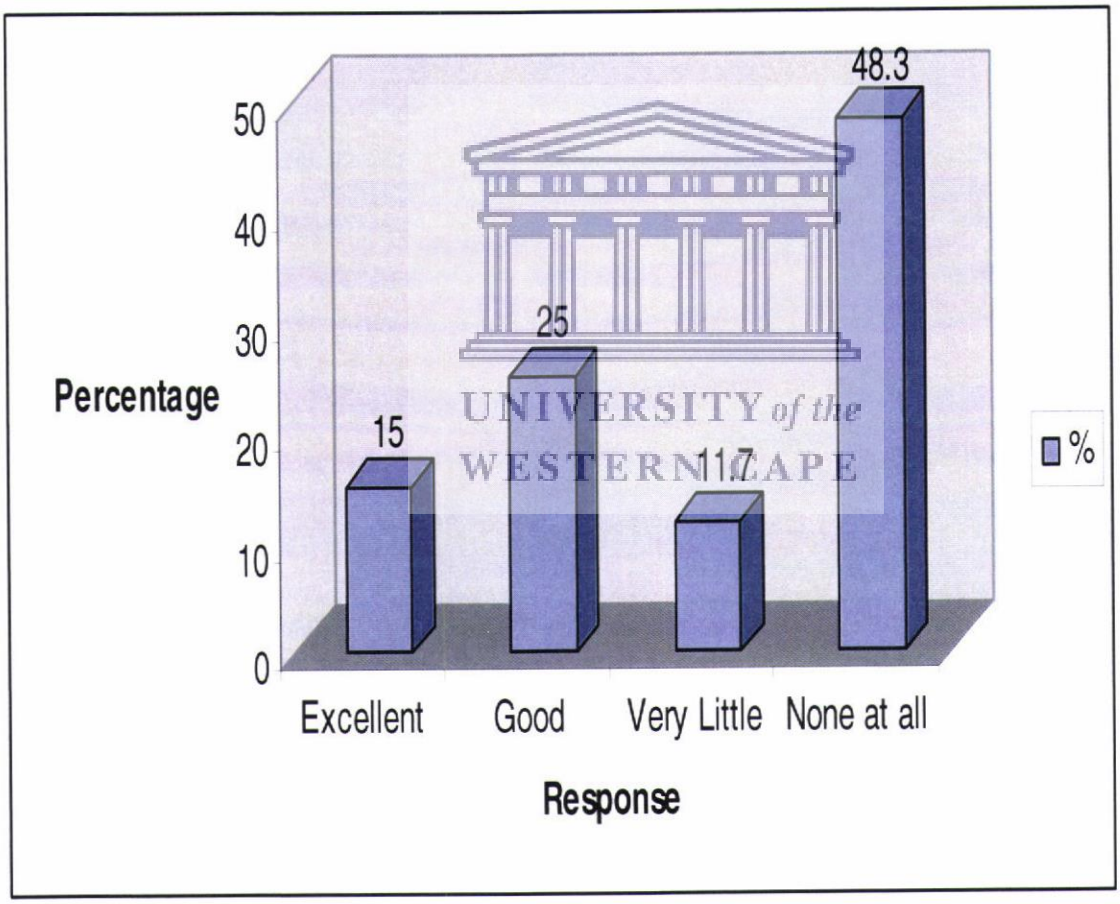


Table 4.10 shows results from the Family Involvement in Care Plan Subscale. The scale has scores from 4 to 20, and scores above 11 mean that there was more involvement of the caregiver in the care plan. In this study, the mean score for involvement in the care plan was 10.6 (standard deviation=4.4). The majority of the caregivers (57.1%) who responded recorded low scores for their involvement in the care plan for the patients by physiotherapists.

Table 4.10 Involvement in Care Plan

Score Range	Frequency	Percentage
4 - 10	40	57.1
11 - 15	21	30
16 - 20	9	12.9

4.8 OBJECTIVE BURDEN

The objective burden scale has total scores ranging from 6 to 30. The average score on the scale was 19.93 (standard deviation = 7.19), indicating that many caregivers were highly disrupted in tangible aspects of their lives compared to the time before assuming the care giving roles. Scores 15 and above indicate high objective burden. A total of 72.9% had total scores of 15 and above.

Table 4.11 Objective burden

Score Range	Frequency	Percentage
6 - 14	19	27.1
15 - 24	30	42.9
25 - 30	21	30

Table 4.12 show caregiver reports on individual items on the objective scale. All the variables showed a constantly higher percentage (42% to 50%) of caregivers responding that infringement or disruption of tangible aspects of their lives was more than the time before assuming care-giving roles. The most affected areas were restriction in caregivers' time for recreational activities followed by restriction in personal privacy (48%).

Table 4.12 Disruption of tangible aspects of caregivers' lives compared to the time before assuming care-giving roles.

	No Disruption %	A Little More %	A Lot More %
Decrease in time for the caregiver	57	20	23
Restriction in personal privacy	52	13	35
Decrease in caregiver's time for Recreational Activities	50	18	32
Restriction in Vacation And Trips Taken	56	17	27
Less Time Spent On Own Work And Chores	57	20	20
Less time spent with friends and relatives	58	17	25

4.9 CAREGIVER STRAIN INDEX (CSI)

Caregiver strain was measured using the 13-item Caregiver Strain Index. Every "yes" response was recorded as 1 and the sum of "yes" responses was scored. Scores of 7 and more on the scale indicate high level of strain (Scherbring, 2002). The average score was 8.7. The majority of the caregivers reported a higher strain level with 58.2% scoring 8 and above on the scale. The mean score was 8.2. **Table 4.13** presents the frequencies of scores on the CSI.

Table 4.13 Caregiver's Strain Index scores

CSI Scores	Frequency	Percentage
0 - 6	22	31.4
7 – 9	29	41.4
10 - 13	19	27.2

Percentage of caregivers who responded "yes" to each of the items on the CSI are illustrated in Table 4.14. Financial strain was recorded by the highest percentage of caregivers (90%), followed by feeling overwhelmed and family changes as a result of care giving which both had 80% of caregivers recording it. The least frequently recorded were work adjustments (40%) and feelings that the patient had changed from the former self (43%). The low number of caregivers, who experienced work adjustment, was attributed to the fact that only a few caregivers were employed.

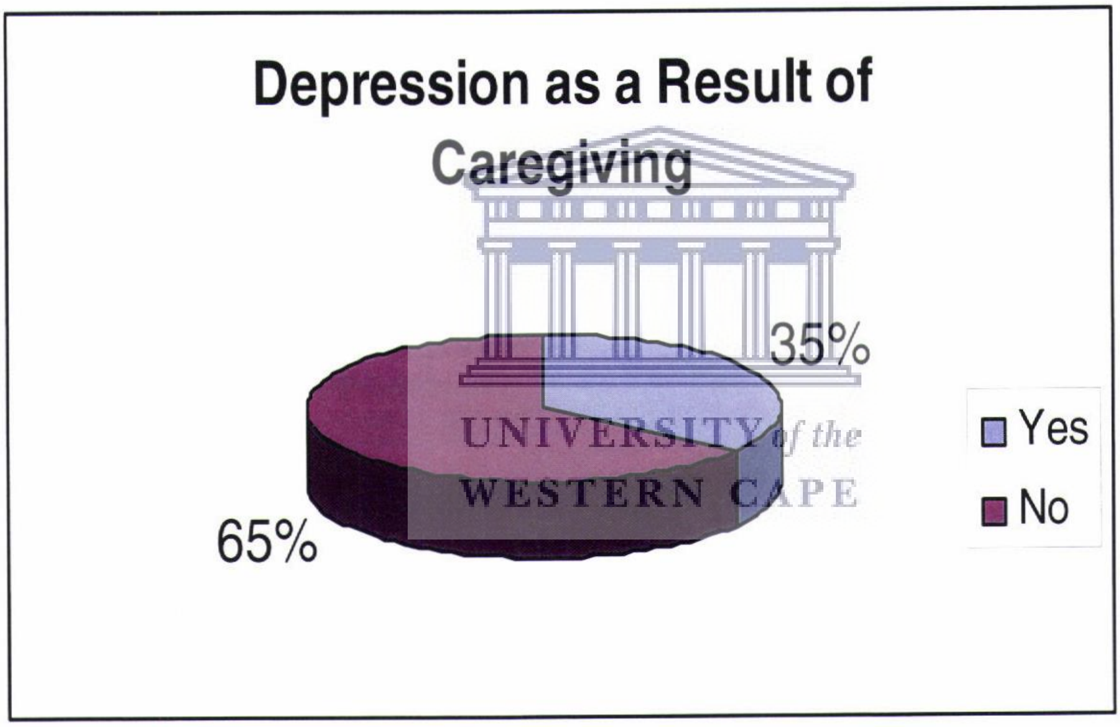
Table 4.14 “Yes” responses to individual items on CSI

Item on CSI	Number	Percentage
Disturbed sleep	35	50
Inconvenient	35	50
Physical strain	42	60
Confining	40	57.1
Family changes	56	80
Changes in personal plans	50	70.1
Other demands	49	70
Emotional adjustments	35	50
Upsetting behaviour	36	50.1
Patient has changed	30	43
Work adjustments	28	40
Financial strain	63	90
Feeling overwhelmed	56	80

4.10 CAREGIVERS SELF PERCEIVED DEPRESSION

Data regarding self-perceived depression is presented in Figure 4.5. The majority of the caregivers felt that they were not depressed. A total of 35% felt depressed as a result of the care-giving role.

Figure 4.5. Caregiver's self perceived depression



4.11 CAREGIVER STRESS BURDEN

The mean score on the stress burden scale was 12.72 and a total of 57.1% reported to be stressed. This Likert scale has four items. Scores range from 4 to 20 on the subscale and the most frequent score range was 4 to 11. Scores above 11 indicate high stress levels (Montgomery et al., 2000).

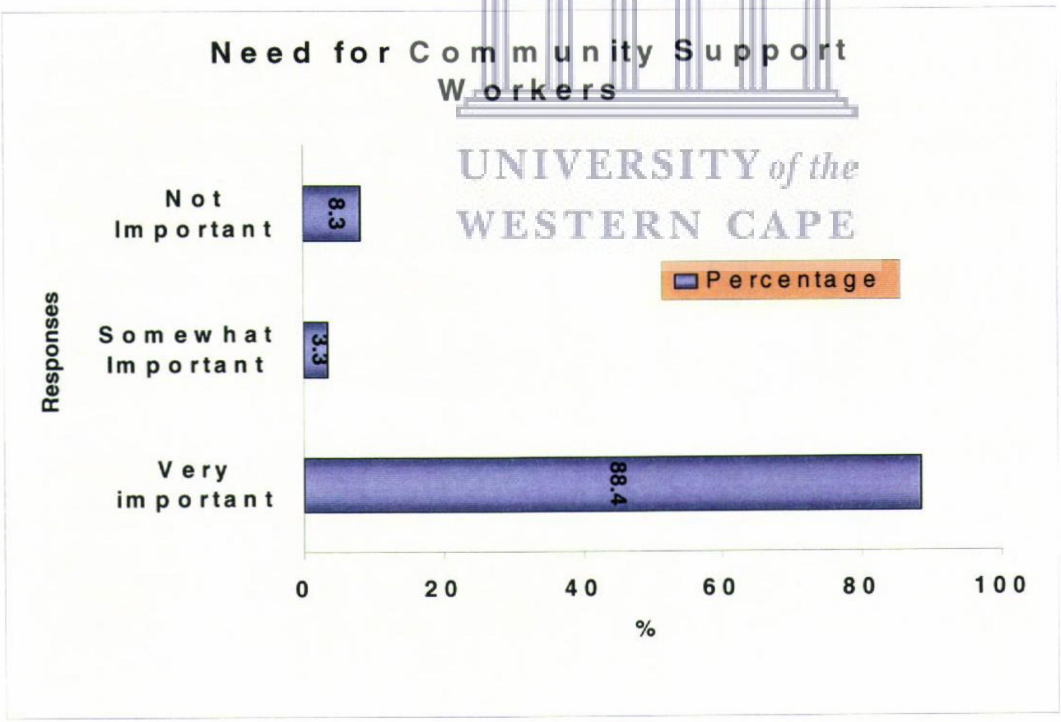
Table 4.15 Caregiver's Stress Burden

Score Range	Frequency	Percentage
4 -11	30	42.9
12-15	14	20
16 -20	26	37.1

4.12 NEED FOR HOME BASED CARE AND COMMUNITY SUPPORT WORKERS

A significantly high percentage of the caregivers' (88.4%) response to the importance of having community support workers, as shown in figure 4.6 is that it was very important. Only 3.3 % considered it as somewhat important and 8.3% perceived it as not important.

Figure 4.6 Need for Community Support workers



4.13 FACTORS INFLUENCING CAREGIVING

Different caregiver and patient characteristics were noted to influence needs and experiences. The Pearson's co-efficiency and cross tabulation were used to determine factors influencing needs and experiences of informal caregivers using the correlation significant at the .01 and .05 level (2-tailed).

The SPSS programme was used to measure the frequencies to describe the socio-demographic variables.

The correlation sub-programme of SPSS was used to determine whether a significant relationship exists between demographic variables, stress, depression and Caregiver Strain Index scores (CSI scores).

The relationship between the following variables were analyzed:

- Demographic data such as age, gender and stress, depression and CSI scores.
- Duration of care giving and stress, depression and CSI scores.

Older age groups reported higher levels of stress as shown in Table 4.16. Nevertheless, the relationship between the age group and stress levels was statistically insignificant.

Table 4.16 Age verses stress levels

n= scores above 11 (those with more stress as a result of care giving)

Age	N	%	P
15 – 30	9	30	0.112**
31 – 45	8	38	0.213**
46 - 60	8	57	0.135**

** Correlation significant at the .01 level (2-tailed)

The Pearson's correlations between duration of care giving and stress, depression and CSI scores were substantially weak. The values for the relationship were such that r = 0.12, 0.14, 0.13 respectively. These results indicate no statistically significant association between the duration of care giving to stress, depression and CSI scores.

Table 4.17 Duration of care giving and stress, depression and CSI scores

Duration of Care giving	n	Stress (n)	Depression (n)	CSI (n)
0 – 4 weeks	24	10	7	14
Over 1 month	22	11	7	12
6–12 months	6	4	3	4
Over 1 year	18	11	8	11

The association between CSI and stress, depression, demand burden, confining nature of care giving and living arrangement was tested at the 0.01 and 0.05 levels (2-tailed) and showed moderately significant associations as shown in Table 4.18. There was a negative correlation between CSI scores and the confining nature of care giving. The majority (72%) of caregivers that were living with the patients had a higher CSI score. They were more physically strained than those that were not living with the patients. There was no statistically significant relation between duration of care giving and scores on SCI.

Table 4.18 CSI vs stress, depression, demand burden, confining nature of care giving and living arrangement

Variable	P value
Stress	.509**
Depression	.427**
Demand Burden	.441**
Confining	-.626**
Living Arrangement	.483**
Duration of Care Giving	.112**

** Correlation significant at the .01 level (2-tailed)

4.14 CONCLUSION

The findings of this study revealed that most caregivers were females, young, uneducated, unemployed and in good health. The majority of stroke patients being cared for by the subjects were young, unemployed, married and dependant in more than one activity of daily living.

Most of the caregivers were satisfied with physiotherapy and rehabilitation services although a lot more reported less attention or none at all received by them from physiotherapists. The majority of caregivers reported the role of care giving as stressful, depressing, strenuous and disruptive to the continuation of their daily routine.

The results of open-ended questions will be reported and discussed with the next chapter. It is often difficult to separate what the caregivers say from the discussion.

CHAPTER 5

DISCUSSION

5.1 INTRODUCTION

This chapter discusses the major research findings in relation to the relevant literature and discussions. Quotations from the questionnaire with open-ended items will be added to affirm the discussions of the results from the questionnaire with closed-ended items. The main aim of this study was to investigate the needs and experiences of informal caregivers of stroke patients attending out-patient physiotherapy at the University Teaching Hospital (UTH) in Lusaka, Zambia.

5.2 SOCIO-DEMOGRAPHICS OF CAREGIVERS AND PATIENTS IN THIS STUDY

This study found that the mean age of caregivers was relatively lower (34 years; Standard deviation = 16) compared to 58.1, 56 and 58 years (standard deviation = 12, 14 and 12 respectively) found in other studies (Grasel, 2002; van der Smagt-Duijnstee et al., 2003; Anderson et al., 1995). In some cases the mean ages were higher; 65, 73, 75 and 80 years (Bressick & Harvey, 1997; DeLaune & Brown 2001; Wyller et al., 2003; Blake et al., 2003).

The involvement of young caregivers has strong implications for them as they are in the productive age group in society. According to Lackey & Gates (2001), parents and health-care providers need to pay attention to the effects of care giving on selected areas of young peoples' lives — particularly school and family life. They found that those who were of dating age, either did not date, or dated early to "get out of the home". Concern has been mounting about the health and welfare of people who provide informal care for family or friends with chronic illness. It is assumed that young and elderly people, who are vulnerable groups in their own right, may be carrying a particularly heavy burden (Doran, Drever, Whitehead & Duncan, 2003).

The dominance of the younger age group assuming the responsibilities of caring for stroke patients may be attributed to the age pattern in the Zambia's population, which has a higher middle-age group (Schlein, 2003).

The majority (71.7%) of the caregivers in this study were female and 28.3% were males. This is consistent with findings of Kasuya et al, (2000) and Giacaman (2001), who all found a preponderance of female caregivers. A high number of female caregivers indicate discrimination against women, because care giving prevents them from having equal opportunities in life, especially in a country like Zambia whose society view care giving as a responsibility for females. Males are under-represented and this should be understood in relation to the higher number of males being expected by society to provide for the family and females' dominant role in domestic duties in the Zambian society.

Illiteracy among respondents was very high. The results revealed that 42 (60%) of the respondents either never went to school or never reached the 12th grade. This level of education in the study was lower than the average level in Zambia. This was very unusual, especially as the setting of the study was in the urban area. This could mean that people, who are not educated, easily fall into the role of care giving. Seventy-seven percent of the caregivers earned no income at all and were unemployed. This may have implications for the economic burden associated with caring. In Covinsky, Eng, Lui, Sands, Sehgal, Walter, Wieland, Eleazer and Yaffe (2001) a total of 604 (22%) of the 2806 caregivers had reduced their number of hours they worked or quit working to care for the patient. The burden of reduced employment is more likely to be incurred by the families of patients with specific clinical characteristics such as level of disability (Covinsky et al., 2001).

Among the females in the study, 22.9% were wives and 33% were daughters. This contrasts with the figures found in literature from other countries. Kerr & Smith (2001) recorded that 63% of the caregivers were patients' wives and 22.5% were daughters. Society in Zambia expects women, especially daughters, to assume responsibilities at home whether employed or not and hence assume the care-giving role in most cases, while men are expected to work in order to provide for the familys' financial needs.

There were no statistically significant differences between the duration the caregiver had been caring for the patient and stress, depression and strain (r = 0.12, 0.14, 0.13 respectively) as indicated in the results. These results are in line with Teel et al, (2001) who found no significant differences in experiences related to the duration of care giving a stroke patient by informal caregivers.

Nevertheless, duration of caring was found to have an effect on the caregivers' physical health according to responses from open-ended items. The majority of the caregivers that complained of poor physical health as a result of care giving had been caring for a longer time than the rest of the group. According to Gräsel (2002), after a long time of care giving, informal caregivers manifest an average degree of physical complaints well above the average for the normal population.

One respondent expressed the following sentiment regarding her physical health. *"I have been taking care of him and he is unable to do anything…I lift him up, bath him, dress him…there are many things that I have to do and now am having back problems…my back pains too much sometimes such that I have difficulties attending to him."*

Another caregiver said: *"Sometimes I feel pain since I have been helping her for a long time…when she is sitting up she needs someone to lift her, she needs someone to raise her up and then bath her. If I don't she has a bad odour like someone dead."*

Some respondents, after realizing how long they would be caring, perceived their future as bleak, yet accepted that nothing would change and relied on spiritual understanding and consulted spiritual leaders, such as pastors, for guidance from the deity to maintain their roles as caregivers.

One respondent said: *"I have been taking care of her for 2 years now and I can not go back to my farm to cultivate because no one can remain with the patient…my work is stuck. Her condition is not improving and am afraid that this will go on like this for a long time. If it were not for the prayers by the pastor and the church, I don't know if I could have made it."*

5.3 HEALTH STATUS

The majority of the caregivers (81.4%) in the study reported having good health, which may be as a result that the majority of them are young. Anderson et al, (1995) found generally ill health status among the caregivers (79%), the majority (20%) of whom were above 60 years of age. The most occurring condition respondents expressed as having was lower back pain. They attributed it to the fact that they have to lift and move the patient. Physiotherapists have the duty to educate and train caregivers about the principles of back care including lifting techniques and also how to maintain their own health (Bressick & Harvey, 1997). This can improve the health wellness of caregivers as poor lifting techniques cause backache. Anderson et al, (1995) states that it is important to determine the specific characteristics of patients and caregivers that make the experiences and needs of caregivers and how this burden can be best managed, either by specific treatments for the patient or by measures aimed at providing support (home help and financial aid) and relief (for example, sitters, day centers, and respite care) for caregivers.

5.4 EXPERIENCES

The experience of caring had mixed outcomes that were positive or negative. The majority of caregivers who were moderately and very satisfied (n=41) with rehabilitation services, notably, were those that had their patients improving functionally.

One respondent said: "*Physiotherapy has brought a drastic improvement where the patients' functional ability is concerned. People should be informed about what physiotherapy can do.*"

Of greater concern by caregivers were the limited attention given to patients during sessions and casting of a blind eye on the caregiver by physiotherapists. Only 28.5% of caregivers reported receiving adequate attention from physiotherapists during their visits to the physiotherapy department. While professionals need to give caregivers enough personal attention and allocate more time attending to stroke patients, it is a challenge at UTH as there are few physiotherapists working at the hospital to adequately address service needs to a large number of clients that they receive on a daily basis. Similar to the findings of this study, Bakas et al, (2002) reported that informal caregivers were concerned with health professionals not considering their needs and experiences while providing stroke services. The little time available for each stroke patient should also focus on needs of the caregiver, as they are important in the development of a successful intervention (Kerr & Smith, 2001).

There is a common perception amongst caregivers of isolation and abandonment following their patient being discharged from in-patient to the out-patient department. One caregiver in this study complained that the focus of professionals was solely on the patient and whenever she brought the patient she was asked to wait outside and only come back when they were done with attending to the patient.

One respondent said: *"I do not know how to do the exercises on her at home since they ask me to wait outside all the time*."

Studies reviewed, present similar results of health professionals overlooking the caregivers (Bakas et al., 2002; Low et al., 1999). According to Simon & Kumar (2002), many of the caregivers of stroke patients, after discharge of their patients, are left to teach themselves how to care for the patients and themselves. Providing attention to caregivers could have a significant impact on them as they could be equipped to handle their needs and those of the patients.

Sometimes, caregivers do not feel comfortable to speak out. This mute behaviour may be related to the caregivers' consideration of cultural taboo against a caring spouse admitting bad experiences and regret. Poor communication between the caregivers and service providers may cause some vital information regarding needs of the patient and carer from reaching the providers in order for them to initiate appropriate interventions.

The involvement of caregivers in the care plan was quite low compared to literature (Montgomery et al., 2000). Caregivers were not adequately educated and prepared to help the patient and address their own needs following discharge of patients. In order to develop a successful intervention and provide sufficient and well-tailored rehabilitation programmes, the caregivers themselves must be involved (Kerr & Smith, 2001; Nolan et al., 1998 and Richardson, Wartburn, Wolfe & Rud, 1996).

One respondent said: *"There are so many weaknesses at the physio department, equipment is not enough and patients are attended to very late. There is an 'I don't care' attitude towards clients."*

Another said: *"There are many patients here at physiotherapy department but only few physiotherapists. Patients are not given enough attention."*

Another said: *"Physios do very little at sessions."*

Another said: *"I don not see what is done to the patient because am asked to wait outside all the time."*

Another said: *"I have a problem with my patient being seen by different physiotherapists every week. One says this and the next week another one says* *something else. I need one physiotherapist to be seeing the patient all the time because inconsistency confuses me.*"

Another said: *"Exercises only are done but there is no encouragement.*"

The positive responses provided by the caregivers regarding physiotherapy services were related to the improvement of the patients' functional status only.

One respondent said*: "Physiotherapy has brought a drastic improvement where the patients' functional ability is concerned. People should be informed about what physiotherapy can do.*"

Another respondent said: *"I am happy that the physios are doing a great job. The patient couldn't walk but now can. Considering her age we thought she wouldn't walk again. Am thanking the hospital for making her walk again.*"

Another respondent said: *"But since she started coming here (physiotherapy department) I have seen that she has improved."*

Caregivers expressed dissatisfaction at the lack of support services that would help them in handling important issues related to care giving, such as counseling and handling of patients' physical and emotional needs. Caregivers feel safe when they know that there is someone they can turn to for support. According to

Bugge et al, (1999) satisfaction of informal caregivers depends on how much benefit is obtained from provision of services.

One respondent said*: "I would like to learn more on how to help… to use the affected side…at the moment we don't know how. If I was taught to do so I would appreciate*."

Another respondent said: *"The patient is very emotional and I don't know how to deal with that*."

The caregivers mentioned that a serious problem was change in the patients' emotional status and how to handle this. They expressed the need to have the skills of handling such situations.

One respondent said: *"She gets angry many times and insults a lot. Her temper rises so much. I wish I could make her change*."

Another caregiver pointed out that the patient had become very sensitive and needed help in dealing with this change: *"When we sit somewhere and talk she accuses us of gossiping about her. If I could be taught how to handle such things that would be better."*
Caregivers need support services to be offered to help them in gaining skills and to become financially stable as a caregivers suggested: *"The government need*

to assist caregivers financially. Churches should be involved with the government to assist caregivers."

One caregiver advised that if caregiver support groups would be formed they could source funds from donor countries. *"The groups should seek financial support from donor countries*."

Literature reveals that intervention such as Team-Managed, Home-Based Primary Care (TM/HBPC) can improve satisfaction with care (Hughes, Weaver, Giobbie-Hurder, Manheim, Henderson, Kubal, Ulasevich & Cummings, 2000).

Amongst the subjects 45% expressed that the care-giving role disrupted their daily routine and in various areas. The areas included education, daily chores, involvement in social activities and recreation. Some had to stop work and others adjusted their working hours, but all were negatively affected in terms of income generation. Consistent with these results Bakas et al, (2002) and Anderson et al, (1995), disruption of daily routine is in various areas such as family functioning, work, social and physical health and independence. The need to be with the patient all the time was a barrier to caregivers from continuing with employment. Leaving the patient would mean that there was no one else to take care of him or her, therefore the caregivers stayed with the patients.

one respondent said: *"I am a farmer, so I can't go and cultivate because no one can remain with the patient…my work is stuck*."

Another respondent said: *"I stopped working ever since the patient got sick*."

The major cause of disruption of daily routine is the amount of time and direct care that informal caregivers offer to assist the patients in performing some ADLs (Eaves, 2000). In this study caregivers had many commitments but could not attend to them as a result of the confining nature of care giving. Respondents indicated the need for respite care to allow them attend to other issues in their lives such as education, daily house chores, going to the bank or shopping and work.

One respondent said: *"I need someone to help in caring. Sometimes I need to do some other things but can't, because if I do, then no one will remain with the patient."*

Caregivers reported that to complete the large number of tasks involved in caring, the caregivers' time for rest is usually short.

One respondent said: *"My sleep is disturbed and more especially the night before coming for a physiotherapy session. When the cock crows immediately you have to wake up to prepare the patient and myself*."

Adjustment to the change in the family was perceived as a difficult process, most particularly, when the patient was the breadwinner. Canam & Acorns (1999) state that, reversing roles, relinquishing old roles, acquiring new roles and obligations can result in serious disruption in the dynamics of the family unit. Delaun & Brown (2001) report that new roles in care giving such as husbands having to assume traditionally female-oriented types of activity and wives having to assume traditionally male-oriented types of activity require coping skills which may not have been learned or used.

Caring requires a lot of input from a caregiver. The workload of caring is strenuous and coping is difficult especially following discharge from the hospital and decreases as patients become more independent.

One respondent said: *"During the early days after discharge it was very difficult to cope… …if you forgot to turn her she would be in that position the whole day."*

Caring for a stroke patient is very strenuous, particularly if the caregiver is older.

One elderly respondent said: *"At least if it was someone young caring for the patient, but me am very old…86 years...it is also a big problem when children have to care for the patient especially when it comes to dressing the patient."*

Another respondent said: *"It is troublesome for her to mess up her beddings…you have to change the beddings and do the laundry."*

Another respondent said: *"Sometimes when we carry her she doesn't have feeling. Urine comes out. I may lift her and ask her to go to the toilet but urine just comes out. Can't you tell us that you want to urinate, and then she says she cannot feel it. It took her 2 years failing to control what's coming out."*

One of the tasks caregivers reported that they disliked was cleaning up an incontinent patient after voiding.

One respondent said: *"If she wanted to open up she would just do it on the beddings and I had to clean it up, or else the whole house would smell."*

Another respondent said: *"Throughout my experience I have come to conclude that stroke caring is a very huge task and it doesn't end quickly."*

Some caregivers reported duties that affected their physical well-being, as follows:

"Sometimes I feel pain…when she is sitting up she needs someone to lift her, she needs someone to raise her up and then bath her. If I don't she has a bad odor like someone dead."

"It's a big task to help her but we need to be strong."

"Stroke attacked her badly…I don't think she can even walk...everything it's me who does, bathing her, applying lotion on her body, dressing her, undressing her, feeding her, lifting her."

The issue of conflicts in families concerning what treatment the patient should undergo emerged. A caregiver experienced difficulties in taking a patient for physiotherapy as a result of a fight within her family.

One respondent said: *"There are two groups fighting in the family. Others say that physiotherapy is a waste of time and we should therefore take the patient to a traditional healer and the other group disagree and say that we should continue with physiotherapy treatment."*

There are uncertainties among caregivers regarding the real causes of stroke and why stroke is affecting mostly the young ones.. These uncertainties are expressed largely by caregivers who take care of younger patients and have background information that stroke affects mostly the elderly.

One respondent said: *"Many of these patients are young people… … I think it is not that they are happening (having strokes) because they have to… … I think we have to face reality… … Most of these cases… … could be HIV related, okay.*

I look at my young brother… … was very Very healthy and promising but this (stroke) came… … It was found that his immunity was low after a blood count was done."

Another respondent said: *"Stroke before never attacked the young ones…it was only for old people… … but these days it's different."*

Financial needs are among the highest needs expressed by caregivers. In this study 90% of the caregivers expressed that they had financial constraints. These needs are greater because most caregivers are out of employment and they need more finances to use for transporting the patient to the health centre for treatment, payment for health services, medication and appliances (Mitchell, 1999). None of the caregivers in this study were receiving any form of financial assistance. This made it difficult to cope with their own needs and those of the patients. Some also had other dependants to care for financially such as children. Many caregivers have financial difficulties in taking care of stroke patients.

One respondent said: *"I spend too much per month for him, about five million Zambian Kwacha... … I have a job and need much time*."

Another respondent said: *"It is difficult to cope with financial needs especially that I have children to take to school and the health cost to take care of*."

Another respondent said: *"It is financially a problem to bring the patient to hospital*."

Only two caregivers interviewed using the questionnaire with open-ended items reported to be helped financially by some relative.

One respondent said: *"The brother in Tunisia sends her money so financially there is no problem*."

5.5 PERCEIVED NEEDS OF CAREGIVERS

The findings from this study both support and disaffirm previous research on the needs of stroke patients and suggest that there is a financial, physical and emotional toll associated with care giving (Bakas et al., 2002; Han & Haley, 1999; Dowswell et al., 2002; Grant et al., 2000; Kerr & Smith, 2001). They indicate that the needs of stroke caregivers are best divided into five categories, the need for information, financial and community rehabilitation, respite care and support programmes such as counseling.

The majority of caregivers (60%) interviewed expressed a great need for information about stroke rehabilitation. Concerns were raised about the way in which the caregivers' patients were discharged from hospital without the caregiver knowing what to do with the patient at home. The caregivers not only needed to know how to help the patient physically, but they also expressed their need to know how to attend to the patients' emotional and physical changes.

One respondent said: *"At discharge not enough information was given to me about what I was going to do with the stroke patient at home."*

Another respondent said: *"I need information on how to help in rehabilitation of the patient and on how to deal with his moods."*

Many caregivers did not know anything about stroke prior to their relative being attacked by it. Among the caregivers interviewed using the questionnaire with open-ended items, 9 caregivers knew what stroke was when their family member was affected. They reported the lack of knowledge on stroke especially the causes.

One respondent said: *"I don not know where this stroke is coming from because my child has no high blood pressure or diabetes."*

Another respondent said: *"We just used to hear that someone had a stroke. I have known about it now that it has come my way."*

Another respondent said: *"I don't know how stroke begins."*

The lack of knowledge on stroke has an impact on rehabilitation in many ways. For example, some caregivers opted for their patients to seek medication from traditional healers as they believed that the disease was as a result of unnatural causes, such as being bewitched and hence, western medical and health care interventions were labelled unprofitable. About half of the caregivers disclosed that once or more times, the family opted to seek treatment from a traditional healer.

Another respondent said: *"At the village the traditional healer was attending to the patient as they thought he was bewitched."*

Caregivers need information on various issues such as caring at home, dealing with the patients' emotional reactions and causes of stroke. The need for information on how to care for the patient's physical and emotional needs at home following discharge by caregivers was also found in other studies (Garwick et al., 1995; Van der Smagt-Duijnstee et al., 2001; Denman, 1998, and Thorne, 1993). Similar to what Dowswell et al, (1997) found, some caregivers in this study perceived the information given to them as inadequate and needed more detailed instructions. Some Caregivers perceived the information they received from physiotherapists and other health professionals as insufficient.

One respondent said: *"I don't think I have enough information about stroke…very very little. The doctors have tried to give me whatever little they think is adequate but some information is still lacking."*

Wellwood et al, (1995) argue that health professionals must ensure that caregivers as well as patients receive appropriate amounts of information. Since informal caregivers spend the most time with the patients after discharge, it is very important that they are fully equipped with information on the causes of a stroke, how it progresses, the treatment goals, what is expected from them and the treatment outcomes. Keeping caregivers informed is an important aspect in building partnerships with them in the rehabilitation process.

For various reasons, almost all respondents expressed a great need for physiotherapy to be conducted in their homes. The reasons included how much time they spent preparing to go to the hospital and the financial burden of transportation. Many caregivers face financial barriers to continuation of attending outpatient physiotherapy services. The current situation needs to be addressed in regard to transportation. A caregiver facing financial problems suggested that they (caregivers) needed community health workers to do visits in their homes than them coming over to the hospital, because it was very costly. Physiotherapists should seriously consider advocating for the introduction of community-based programmes by the health system in order to reach not only their clients, but also those that could have been reached but are unable to access the services as a result of financial constraints. Low et al, (1999) argued that focus on the structure and process of professional support as perceived by caregivers is important to the development and provision of stroke services.

Respondents were very keen to find out if, in the future funds could be made available to those caring for stroke patients because they perceived financial needs detrimental to their continuation of receiving services. Most of the caregivers reported having difficulties commuting between their homes and the hospital. They also considered lack of funds as the major barrier to attendance of physiotherapy sessions. In Zambia, there exists no disability funds set aside to help caregivers of stroke patients. This has been a draw back in the progression of therapeutic intervention. Other studies report managing finances, adapting to a special diet, insufficient government funding and transporting the patient as the main areas perceived as attributes to the need for finance (Bakas et al.,2002; Low et al., 1999).

Respite care was perceived as of great need by many respondents. They needed help in caring for the patient and time off. Caregivers needed to do some urgent things, but because there was no one to stand in for them, it was difficult to cope. Others needed time off to relax and rest from the continuous caring process. In the study some caregivers took time off by delegating some care giving duties to some other family members, others did not have someone to replace them in their absence and had to spend all their time with the patient.

According to McConkey & Adonis (1999), common forms of respite include day-care services, in-home respite care, overnight care at home or in an institution and short breaks. The desperate need for respite care by caregivers is illustrated in Chiu et al, (1999) where 42.5% of the family caregivers interviewed indicated a willingness to pay at least 50% of monthly family income for respite care.

The majority (91.7%) of the caregivers reported needing help with caring. They expressed a need for someone to stand in for them to have a chance to do other duties.

One respondent said: *"I require a person to help me so that I am not alone helping the sick person."*

Another respondent said: *"The other help I need is for someone to help me in dressing her, bathing her...it is a very big task to bath her and it takes all my time.*

All caregivers interviewed using the open-ended item questionnaire, but one, were not able to find respite care whenever they wanted to go and attend to other matters. One caregiver was able to get respite care by delegation of duties to other members of the family and she said:

"My husband and I have decided to continue with our normal activities. What we have done is delegate duties to everyone at home."

Another caregiver said: "I have someone who does come to be with the patient when I need to go out like shopping and sometimes I have to go and see my sick mother… … I do pay her. In fact my sister in law helps me to pay the girl."

According to Low et al, (1999) health services are often the first point of contact for many stroke caregivers and so have a potential role in maintaining caregivers' quality of life. Caregivers in this study expressed inadequacies in the provision of these needs. Services needed, as expressed by caregivers in this study, included support services related to care giving that would help them in handling important issues related to care giving such as counseling, post discharge needs, financial support, and handling of patients' physical and emotional needs. In some studies, caregivers highlighted inconsistencies in the provision of such services (Simon & Kumar, 2002: Thorne, 1993). The majority of the caregivers reported that they did not receive adequate preparation prior to the discharge of their relative and, as a result, they were concerned about their own ability to cope with the physical aspects of caring. This study supports the argument that efforts to improve not only the patients' quality of life but also that of the caregivers should be designed according to considerations and values that the service receivers attach to them (Lilley et al., 2003).

Caregivers complained that bringing the patient to the hospital was a very tough thing to do physically and financially. They, for this reason, emphasized that they needed to have community health workers conducting treatment sessions in their homes.

One respondent said: *"We need community health workers to do visits in our homes than us coming here, because it is very costly."*

Another respondent said: *"If physiotherapists could come to homes it would be better."*

Another respondent said: *"Help is needed especially if the physiotherapists can be coming to our home to treat the patient with their equipment such as the ropes, the bicycle, the stones and things to squeeze and pick."*

Another respondent said: *"What would be nice for us who wake up very early in the morning is to just wait at home and say that the physiotherapists are coming to help."*

5.6 FACTORS INFLUENCING EXPERIENCES AND NEEDS

Factors affecting needs and experiences were measured with Pearson's co-efficiency. The higher percentage of young caregivers (80%) expressing major restrictions in their lives compared to the older caregivers (34%) may be as a result of young caregivers having much to do in society. The responsibility is a hindrance to future goals of the young population. Many of them reported that they wanted to further or continue their education but could not as a result of their responsibilities and no one else available to care for the patient. Caregivers living with the patients are more likely to be strained than those not living with the patient mostly because of the continuous need for them to assist the patient. Those that were not living with patients had time to do other things. For the same reason, more caregivers living with the patients reported being physically strained compared to those not living with the patients. Those that cared for patients, whom they perceived as being more dependent in more ADLs, were more likely to experience strain, stress and depression and expressed the need for a support worker visiting them at home. Fewer caregivers who were more educated needed information than those with lower education. Where the patient or caregiver is the breadwinner before suffering a stroke, financial difficulties appear more often. Anderson et al, (1995) states that, financial and work-related problems are most relevant among caregivers who are the main wage earner or the stroke patient.

If practice in this area is to improve, it is important to develop partnership models of working with informal caregivers when their patients are admitted as in-patients, whilst continuing with rehabilitation as outpatients. According to Brereton & Nolan (2002), this does not only help to ensure that stroke survivors receive the best care, but also that their caregivers are well prepared for their new role post discharge.

5.7 SUMMARY

Chapter five discusses the socio-demographic characteristics of informal caregivers, their health status, experiences and needs. The age of caregivers was found to be relatively young compared to reviewed literature of studies done in other countries. Gender distribution was found to correspond to that found in literature.

The majority of the caregivers reported having good health. Other studies have reported generally poor health among respondents. This may be as a result of the much older respondents they recruited compared to the younger age group in this study. Experiences and needs of informal caregivers were discussed with support from narratives gathered from the questionnaire with open-ended items.

CHAPTER 6

CONCLUSIONS

6.1 SUMMARY

The aim of the study was to identify the perceived experiences and needs of informal caregivers of stroke patients attending physiotherapy sessions as outpatients at the University Teaching Hospital. The researcher reviewed relevant literature from studies, which focused on socio-demographic data, experiences and needs of informal caregivers of stroke patients. There was no literature found on studies done in Zambia on stroke care giving. The study employed a cross-sectional descriptive study design utilizing a questionnaire with closed-ended items and another with open-ended items. A total of 70 caregivers were interviewed using the closed-ended item questionnaire and 10 were purposively selected from the subjects and interviewed using the questionnaire with open-ended items. The researcher interviewed all caregivers. The research setting was the physiotherapy department at the University Teaching Hospital in Lusaka Zambia. The Statistical Package of Social Sciences (SPSS) was used to obtain data in the form of frequencies, cross tabulations and correlations. The results showed that the majority of the caregivers were young, female, uneducated and unemployed. This study provides a description of socio-demographic data, needs and experiences of informal caregivers caring for stroke patients. The results raise important concerns in regard to no research done in the area of stroke care giving in Zambia. Assuming a care giving role has various implications to the caregivers' life. They experience, stress, depression, their daily routine is disrupted, and they lack various skills and information about stroke. Their needs include financial support, respite care and other support services. According to the reports by caregivers in this study many services have not been offered to them at the University Teaching Hospital. The study highlights the difficulties and amount of input needed to address caregivers' experiences and needs. Stroke affect caregivers in various ways yet can be include in rehabilitation in order to yield positive outcomes. Physiotherapists are in a position to employ an exemplary and comprehensive approach to stroke rehabilitation by focusing on the entire family as a unit of care, collaborating with other disciplines such as social workers, community rehabilitation workers, and other health care workers and providing anticipatory guidance, and facilitating appropriate referrals.

There is increasing recognition of the role of informal caregivers supporting stroke survivors. The transition to care giving is a complex process, unique to each caregiver. Many caregivers adopt their roles without adequate choice and preparation. The main aim of the study to identify the perceived needs and experiences of informal caregivers of stroke patients attending physiotherapy sessions at UTH in Lusaka as out patients was achieved. This study shows that experiences and perceived needs of informal caregivers of stroke patients have not been adequately addressed by physiotherapists.

6.2 IMPLICATION FOR PHYSIOTHERAPY

Physiotherapists working in communities and health institutions are intricately involved in stroke rehabilitation and should be attentive and supportive to the caregivers. The knowledge from this study provide valuable information that can be used by physiotherapists and other health care professionals involved with informal caregivers of stroke patients in order to ensure that informal caregivers' needs and experiences are attended to with adequacy. The increase in stroke cases, and resultant increase of caregivers calls for physiotherapists to be more equipped to address challenging issues in this rarely studied area. The limited workforce makes physiotherapy services insufficient for the demand resulting from the increasing number of stroke patients and their caregivers.

6.3 RECOMMENDATIONS

Caregivers should be made to feel that they are recognized as important in the care-giving situation. Physiotherapists can have influence on informal caregivers' experiences by including them in the rehabilitation process. This includes helping them with care-giving skills and information about stroke. Keeping the caregivers informed is a crucial aspect of building partnership with informal caregivers.

Assessments and reassessments should include caregivers and they should be referred to other services they may need such as psychology and social work. It is imperative that health care professionals assess caregivers' adaptation to their roles in order to provide needed education and develop more comprehensive discharge planning for stroke patients and their caregivers. These interventions may assist families to prepare for responsibilities that occur after discharge, ease hospital-to-home transitions, and facilitate more effective role adjustment.

From the findings of the study the following recommendations are made:

1. Health professional need to develop support programmes for stroke patients in the community that should include issues cardinal to their caregivers.

2. Health professionals involved in stroke rehabilitation should look at ways to develop information systems that inform and educate caregivers about stroke, care giving and their role in the process of rehabilitation.

3. Health professionals should identify sources and means of allocating, resources and support services to caregivers of stroke patients with the involvement of the government health system and non governmental organizations.

6.4 LIMITATIONS

The ten caregivers interviewed were selected from the sample purposively thus creating an impossibility for generalization. Some caregivers had only been attending to the patients for a short period of time when they were interviewed and they could have underestimated how severe the patients' experiences would be in the long run. In the case of those that had been caring for a long time such as more than two years, it could have led to bias as the caregivers tried to recall what their experiences were since the patients' discharge.

Despite the limitations, the researcher believes that this study makes a valuable foundation of literature on care stroke care giving in Zambia. Shortcomings in stroke services confirm others' findings and have been discussed in the previous chapter. The study provides valuable literature and insight into the perceived needs and experiences of caregivers in Zambia.

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APPENDIX I

DEMOGRAPHIC DATA: CAREGIVER

(Mark items with a X)

1. GENDER

Male	
Female	

2. AGE ________

15 – 30 yr	
31 – 45 yr	
46 – 60 yr	
61 – 75 yr	
76 – 90 yr	

3. HOME LANGUAGE(S)

ENGLISH	
NYANJA	
OTHER/SPECIFY	

4. MARITAL STATUS

Married	
Single	
Divorced	
Widowed	

5. EDUCATION LEVEL

Less than grade 12	
Grade 12	
Some college	
4 yr Degree or Higher	

6.EMPLOYMENT

Employed	
Unemployed	

7. INCOME/NET

Below K250, 000.00	
K250, 000.00 to K350,000.00	
K351, 000.00 to K450, 000.00	
Over K450, 000.00	

8. RELATIONSHIP TO DEPENDANT

Parent / Parent -in -law	
Child	
Spouse / Partner	
Friend / Neighbour / Other	

9.CARER LIVES WITH DEPENDANT

Yes	
No	

DEMOGRAPHIC DATA: DEPENDANT

1. ADDRESS

2. Date of discharged_________________

3. Duration of the illness_______________

4. GENDER

Male	
Female	

5. AGE

15 – 30 yr	
31 – 45 yr	
46 – 60 yr	
61 – 75 yr	
76 – 90 yr	

6. MARITAL STATUS

Married	
Single	
Divorced	
Widowed	

7.EMPLOYMENT

Employed	
Unemployed	

8. DEPENDANT IN THE FOLLOWING ACTIVITIES OF DAILY LIVING (ADL)

Bathing	
Feeding	
Mobility	
Toileting	
Dressing	

Your Health and Well-being

1. In general how would you rate your health status?

Excellent	
Very good	
Good	
Fair	
Poor	

Illnesses and Medical Problems (tick all that apply)
[ ] Allergies
[ ] Anaemia
[ ] Arthritis
[ ] Ashthma
[ ] Bleeding disorder
[ ] Cancer or tumour
[ ] Colitis
[ ] Convulsions or seizure
[ ] Diabetes
[ ] Eating disorder
[ ] Heart disease
[ ] Hepatitis
[ ] High blood pressure
[ ] High cholesterol
[ ] Kidney/Bladder Disease
[ ] Mental Illness
[ ] Migraine Headach
[ ] Pneumonia
[ ] Rheumatice Fever
[ ] STD
[ ] Stomach/Duodenal Ulcer
[ ] Thyroid Problem
[ ] Tuberculosis

Skin
[ ] Rash or Hives

Nervous system
[ ] Frequent, Severe Headaches
[ ] Dizziness
[ ] Double Vision
[ ] Numbness
[ ] Loss of Coordination
[ ] Seizures

Lungs
[ ] Persistant cough
[ ] Wheezing
[ ] Shortness of breath
[ ] Problem breathing at night or when lying down
[ ] Spitting up blood
[ ] Positive TB test

Heart
[ ] Chest Pain
[ ] Palpations (heart racing)
[ ] Irregular heartbeat/skipping a beat
[ ] Heart murmur

Gastro-intestinal
[ ] Stomach pain/abdominal pain
[ ] Indigestion/heart burn
[ ] Difficulty swallowing
[ ] Vomiting/Nausea
[ ] Changes in Bowel Habits
[ ] Blood Stools

Urinary
[ ] Pain/burning on urination
[ ] Blood in urine
[ ] Frequent urination
[ ] Previous infections
[ ] Kidney stones

Eyes
[ ] Glasses/contacts
[ ] Eye pain
[ ] Change in vision

Ears
[ ] Loss of hearing
[ ] Ringing
[ ] Drainage

Nose/throat/sinuses
[ ] Hoarseness
[ ] Nasal stuffiness or runny nose
[ ] Sore throat

Mouth
[ ] Bleeding gums
[ ] Toothache

Joints and back
[ ] Pain
[ ] Swelling
[ ] Stiffness
[ ] Deformity

Muscles
[ ] pain
[ ] weakness
[ ] twitching

Endocrine
[ ] heat/cold intolerance
[ ] excessive thirst
[ ] excessive hunger

Blood
[ ] easy bleeding
[ ] anaemia

Psychological
[ ] nervousness
[ ] depression
[ ] unable to sleep
[ ] memory loss

Other Diseases
1.
2.
3.
4.
5.
6.

APPENDIX II

Caregiver Strain Index (CSI)

Questionnaire: I am going to read a list of things, which other people have found to be difficult in helping out after somebody comes home from the hospital.

Would you tell me whether any of these apply to you? (PLEASE GIVE EXAMPLES)

(1) Sleep is disturbed because _________ is in and out of bed or wanders around at night.☐

(2) It is inconvenient (e.g. because helping takes so much time or it's a long drive over to help)☐

(3) It is a physical strain (e.g. because of lifting in and out of a chair; effort or concentration is required)☐

(4) It is confining (e.g. helping restricts free time or cannot go visiting)☐

(5) There have been family adjustments (e.g. because helping has disrupted routine; there has been no privacy).☐

(6) There have been changes in personal plans (e.g. had to turn down a job; could not go on vacation).☐

(7) There have been other demands on my time (e.g. from other family members).☐

(8) There have been emotional adjustments (e.g. because of severe arguments).☐

(9) Some behavior is upsetting (e.g. because of incontinence; _________ has trouble remembering things; or _________ accuses people of taking things).☐

(10) It is upsetting to find _________ has changed so much from his/her former self (e.g. he/she is a different person than he/she used to be).☐

(11) There have been work adjustments (e.g. because of having to take time off).☐

(12) It is a financial strain.☐

(13) Feeling completely overwhelmed (e.g. because of worry about _________; concerns about how you will manage).☐

APPENDIX III

Rehabilitation and Support (satisfaction with intervention)

1. In your opinion the most important effects of the intervention are

☐ Physical condition improving
☐ Mood improving
☐ Social activity increasing
☐ Access to support and care improving
☐ No effects

2. How would you rate the information and the support provided by the physiotherapist?

☐ Excellent
☐ Good
☐ Too little
☐ None at all

3. How do you rate the intervention courses as a form of rehabilitation ?

☐ Excellent
☐ Good
☐ Too little
☐ Not at all

4. As the caregiver of a stroke patient what kind of attention are you receiving during the follow-up ?

☐ Excellent
☐ Good
☐ Too little
☐ None at all

5. How important do you find the need of a support worker for stroke survivors in the community?

☐ Very important
☐ Less important
☐ Not necessary

APPENDIX IV
Family Caregiver Scale

	Demand Burden	
Item Name:	**Item Description:**	**Item Recoding:**
1	Increased attempts by relative to manipulate	1 2 3 4 5
2	Increased number of unreasonable requests	1 2 3 4 5
3	Increased feeling of being taken advantage of	1 2 3 4 5
4	Increase in demands made by relative	1 2 3 4 5

	Stress Burden	
Item Name:	**Item Description:**	**Item Recoding:**
5	Increased stress in relationship	1 2 3 4 5
6	Added tension in life	1 2 3 4 5
7	Increased depression concerning relation	1 2 3 4 5
8	Increase in anxiety	1 2 3 4 5

	Objective Burden	
Item Name:	**Item Description:**	**Item Recoding:**
9	Decrease time you have for yourself	1 2 3 4 5
10	Restriction in personal privacy	1 2 3 4 5
11	Decrease your time for recreational activities	1 2 3 4 5
12	Restrict vacation and trips taken	1 2 3 4 5
13	Less time spent on own work and chores	1 2 3 4 5
14	Less time with friends and other relatives	1 2 3 4 5

	Involvement in Care Plan	
Item Name:	**Item Description:**	**Item Recoding:**
15	How often direct care was provided past month	1 2 3 4 5
16	Visits within the past month	1 2 3 4 5
17	Discuss care with staff member in past month	1 2 3 4 5
18	Assisted with grooming in past month	1 2 3 4 5

APPENDIX V

EIGHT ITEM QUESTIONNAIRE

1. Tell me about a typical day of providing care for your [mother, father, husband, relative].

2. What have your most concerned experiences or problems been about since your [mother, father, husband, relative] has come home?

3. What have you found helpful in dealing with those experiences or problems?

4. What advice would you give someone who has just had a family member come home after suffering a stroke?

5. If we were to develop a program to help caregivers like yourself, what would be most helpful?

6. What do you think about the future?

7. Describe your feelings about caring for X at home.

8. What other issue do you wish to discuss?

APPENDIX VI

Physiotherapy Department
University of the Western Cape
Private bag X17,
Bellville 7535.

28th May 2003

The Head of the Physiotherapy Department
Chainama Hills Hospital
Lusaka 10101
Zambia

Dear Madam

Re: Permission to conduct a pilot study :

Permission is hereby requested to conduct a pilot study at Chainama Hills Hospital in Lusaka. The pilot study is part of a research project, which needs to be completed in partial fulfilment of a MSc. in Physiotherapy at the University of the Western Cape. The research will be conducted by the master's student, Oswell Khondowe (Student number 2257702).
Our university's Faculty Higher Degrees committee has approved the study. For any queries please do not hesitate to communicate with us.

Thanking you in advance.
Yours sincerely

Anthea Rhoda
Supervisor

Physiotherapy Department
University of the Western Cape
Private bag X17,
Bellville 7535.

28th May 2003

The Head of the Physiotherapy Department
University Teaching Hospital
Private Bag RW 1x
Lusaka 10101
Zambia

Dear Madam

Re: Permission to conduct a study:

Permission is hereby requested to conduct a study at the University Teaching Hospital. The study is part of a research project, which needs to be completed in partial fulfilment of a Masters of Science in Physiotherapy at the University of the Western Cape. The research will be conducted by the masters student, Oswell Khondowe, (Student number 2257702).

Our university's Faculty Higher Degrees committee has approved the study. For any queries please do not hesitate to communicate with us.

Thanking you in advance.
Yours sincerely

Anthea Rhoda
Supervisor

Physiotherapy Department
University of the Western Cape
Private bag X17,
Bellville 7535.

17th June 2003

Dear caregiver,

RE: Request for consent

I am a Physiotherapy student at the above-mentioned institution in South Africa and write to seek permission to interview you as a caregiver to your patient. This study is aimed at identifying the expressed needs and experiences of informal caregivers of stroke patients and factors influencing their abilities to act as caregivers. The results may help in understanding the experiences and needs of caregivers and could contribute to the implementation of rehabilitation programmes that would address the needs of caregivers too.

The results of the study will be made available to the caregivers. There are many other caregivers who will be included in the study. You are free to be excluded from the study at any point if you wish to. Be assured that your name will remain anonymous.

Please sign in the line above the name caregiver if you accept to be interviewed.

Thanking you in advance for your participation in the study.

……………………………..   ………………………….

Oswell Khondowe   Caregiver

Physiotherapy student (Masters of Science in Physiotherapy)

APPENDIX VII

THEMES FROM OPEN-ENDED QUESTIONNAIRE

1. EXPERIENCES OF CAREGIVERS

1.1 DISSATISFACTION WITH PHYSIOTHERAPY SERVICES.

The responses relate to physiotherapy treatment sessions, type of treatment and involvement of caregivers.

There are so many weaknesses at the physio department, equipment is not enough and patients are attended to very late. There is an 'I don't care' attitude towards clients (female caregiver: wife).

There are many patients here at physiotherapy department but only few physiotherapists. Patients are not given enough attention (female caregiver: sister).

Physios do very little at sessions (female caregiver: mother).

I don't see what is done to the patient because am asked to wait outside all the time (female caregiver: wife).

I have a problem with my patient being seen by different physiotherapists every week. One says this and the next week another one says something else. I need *one physiotherapist to be seeing the patient all the time because inconsistency confuses me* (male caregiver: husband).

Exercises only are done but there is no encouragement (female caregiver: daughter).

1.2 SATISFACTION WITH PHYSIOTHERAPY SERVICES

Physiotherapy has brought a drastic improvement where the patients' functional ability is concerned. People should be informed about what physiotherapy can do (female caregiver: wife).

I am happy that the physios are doing a great job. The patient couldn't walk but now can. Considering her age we thought she wouldn't walk again. Am thanking the hospital for making her walk again (female caregiver: daughter).

But since she started coming here (physiotherapy department) I have seen that she has improved (female caregiver: daughter).

1.3 SUPPORT SERVICES

I would like to learn more on how to help… to use the affected side…at the moment we don't know how. If I was taught to do so I would appreciate (female caregiver: wife).

The patient is very emotional and I don't know how to deal with that (male caregiver: son).

She gets angry many times and insults a lot. Her temper rises so much. I wish I could make her change (female caregiver: daughter).

When we sit somewhere and talk she accuses us of gossiping about her. If I could be taught how to handle such things that would be better (female caregiver: sister).

The government need to assist caregivers financially. Churches should be involved with the government to assist caregivers (female caregiver: mother).

The groups should seek financial support from donor countries (female caregiver: wife).

1.4 DAILY ROUTINE WAS DISRUPTED

I stopped working ever since the patient got sick (female caregiver: wife).

I am a farmer, so I can't go and cultivate because no one can remain with the patient…my work is stuck (male caregiver: husband).

1.5 WORK OVERLOAD

During the early days after discharge it was very difficulty to cope…if you forgot to turn her she would be in that position the whole day (female caregiver: daughter).

If she wanted to open up she would just do it on the beddings and I had to clean it up, all else the whole house would smell (female caregiver: daughter).

Throughout my experience I have come to conclude that stroke caring is a very huge task and it doesn't end quickly (female caregiver: wife).

Sometimes I feel pain…when she is sitting up she needs someone to lift her, she needs someone to raise her up and then bath her. If I don't she has a bad odor like someone dead (female caregiver: mother).

I have been taking care of him and he is unable to do anything…I lift him up, bath him, dress him…there are many things that I have to do and now am having back problems…my back pains too much sometimes such that I have difficulties attending to him (female caregiver: wife).

It's a big task to help her but we need to be strong (female caregiver: daughter).

Stroke attacked her badly…I don't think she can even walk...everything it's me who does, bathing her, applying lotion on her body, dressing her, undressing her, feeding her, lifting her (female caregiver: daughter).

At least if it was someone young caring for the patient, but me am very old…86 years...it is also a big problem when children have to care for the patient especially when it comes to dressing the patient (female caregiver: mother).

It is troublesome for her to mess up her beddings…you have to change the beddings and do the laundry (female caregiver: mother).

Sometimes when we carry her she doesn't have feeling. Urine comes out. I may lift her and ask her to go to the toilet but urine just comes out. Can't you tell us that you want to urinate then she says she can't feel it. It took her 2 years failing to control what's coming out (female caregiver: daughter).

My sleep is disturbed and more especially the night before coming for a physiotherapy session. When the cock crows immediately you have to wake up to prepare the patient and myself (female caregiver: wife).

2 NEEDS OF CAREGIVERS OF STROKE PATIENTS

2.1 CARING AT HOME

At discharge not enough information was given to me about what I was going to do with the stroke patient at home (female caregiver: wife).

I need information on how to help in rehabilitation of the patient and on how to deal with his moods at home (female caregiver: wife).

2.2 INSUFFICIENT INFORMATION ABOUT STROKE

I don't think I have enough information about stroke…very very little. The doctors have tried to give me whatever little they think is adequate but some information is still lacking (female caregiver: daughter).

I don't know where this stroke is coming from because my child has no hypertension or diabetes (female caregiver: mother).

We just used to hear that someone had a stroke. I have known about it now that it has come my way (female caregiver: wife).

I don't know how stroke begins (male caregiver: son).

At the village the traditional healer was attending to the patient as they thought he was bewitched (female caregiver: daughter).

2.3 FAMILY DISAGREEMENTS AND UNCERTAINTIES

There are two groups fighting in the family. Others say that physiotherapy is a waste of time and we should therefore take the patient to a traditional healer and the other group disagree and say that we should continue with physiotherapy treatment (female caregiver: wife).

Many of these patients are young people. I think it is not that they are happening (having strokes) because they have to. I think we have to face reality. Most of these cases… could be HIV related, okay. I look at my young brother…was very very healthy and promising but this (stroke) came. It was found that his immunity was low after a blood count was done (female caregiver: sister).

Stroke before never attacked the young ones…it was only for old people…but these days it's different (female caregiver: mother).

2.4 NEED FOR FINANCES

I spend too much per month for him, about K5m. I have a job and need much time (male caregiver: son).

It's difficult to cope with financial needs especially that I have children to take to school and the health cost to take care of (male caregiver: husband).

It's financially a problem to bring the patient to hospital (female caregiver: sister).

The brother in Tunisia sends her money so financially there is no problem. (female caregiver: mother).

2.5 NEED FOR HOME BASED CARE AND COMMUNITY SUPPORT WORKERS

We need community health workers to do visits in our homes than us coming here, because it is very costly (male caregiver: son).

If physiotherapists could come to homes it would be better (female caregiver: daughter).

Help is needed especially if the physiotherapists can be coming to our home to treat the patient with their equipment such as the ropes, the bicycle, the stones and things to squeeze and pick (female caregiver: mother).

What would be nice for us who wake up very early in the morning is to just wait at home and say that the physiotherapists are coming to help (female caregiver: wife).

2.6 NEED FOR RESPITE CARE

I require a person to help me so that I am not alone helping the sick person (male caregiver: brother).

I need someone to help in caring. Sometimes I need to do some other things but can't, because if I do then no one will remain with the patient (female caregiver: wife).

The other help I need is for someone to help me in dressing her, bathing her...it is a very big task to bath her and it takes all my time (male caregiver: husband).

My husband and I have decided to continue with our normal activities. What we have done is delegate duties to everyone at home (female caregiver: sister).

I have someone who does come to be with the patient when I need to go out like shopping and sometimes I have to go and see my sick mother. I do pay her. In fact my sister in law helps me to pay the girl (female caregiver: wife).