UNIVERSITY OF MALAWI

KAMUZU COLLEGE OF NURSING

LIVED EXPERIENCE OF RELATIVES OF PATIENTS WITH STROKE.

BY

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A RESEARCH PROPOSAL SUBMITTED TO THE FACULTY OF NURSING IN PARTIAL FULFILLMENT OF THE REQUIREMENT FOR THE AWARD OF BACHELOR OF SCIENCE DEGREE IN NURSING.

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JUNE 2006.

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ACKNOWLEGDEMENT

I would like to thank Mr. Ngwale for proving me with the basic information in relation to research.

I would also like to express my sincere gratitude to everyone who helped me during the time I was writing this proposal, particularly my supervisor, Mrs. Chalanda. Special thanks should also go to Mrs. Kabuluzi who tirelessly assisted me when Mrs. Chalanda was away.

I am also grateful to the library staff for giving me access to Internet where some of the information was sourced.

Above all, thanks be to the almighty God for giving me the courage, intelligence and good health life during the time I was writing this proposal. May Your name be Glorified.

ABSTRACT.

Stroke is the third most common cause of death in industrialized countries and a major cause of adult disability. However, the burden of caring for stroke survivors usually rests with family members who have neither chosen nor volunteered for the role of 'carers'.

The aim of the study is to find out about the knowledge and experiences of relatives of stroke patients in relation to stroke. This will help to fill in the gaps that exist concerning management of stroke survivor patients, hence improving the lives of these stroke survivor patients.

The study will be descriptive in nature, and qualitative research method will be used. Qualitative methodology focuses on individuals' lived experiences as they are presented in thoughts, ideas, feelings, attitudes and perceptions. In addition, the research approach emphasizes human behaviour and social interaction. The general systems theory will be used to guide the study.

The study will use a sample of 15 relatives of stroke patients who will accompany their stroke patients to physiotherapy and/or to hypertension clinic at Kamuzu Central Hospital. The subjects will be selected through purposeful sampling. Data which will be collected from this study will be analysed manually. It will be interpreted and illustrated using graphs, tables and diagrams.

CHAPTER 1

1.0 TITLE

The lived experience of relatives of patients with stroke.

1.1 INTRODUCTION

It is estimated that 25-74% of stroke survivors require help with activities for daily living from informal caregivers, often, family members (Leeder, 2004). The physical, psychological, emotional, and social consequences of care giving and its economic benefit to society are not well recognised, caregivers' needs are often given low priority in the management of stroke patients. Advances in stroke rehabilitation have successfully reduced severe disability and institutionalisation, which has increased the number of disabled patients living at home and being supported by care givers who feel inadequately trained, poorly informed, and dissatisfied with the extent of support available after discharge (Dirksen, 2004).

Interventions to support stroke caregivers have an impact on both patients and the caregivers. These inventions are for example providing education, counselling and emotional support. Accessing services by using information packages, social workers, specialist nurses, or family support workers also has an impact on patients and improvements in psychological and social measures in care givers (World Health Organization, 1990).

Caring for stroke patients is a demanding responsibility. A research study on the lived experience of relatives of patients with stroke is essential for carers as well as

the health personnel in such a way that it will give information on how the carers go about their day-to-day management of disabled stroke survivors. The study is likely to have a role in reducing the burden of care, and to improve patient and caregiver outcomes.

1.2 BACKGROUND.

Stroke is a debilitating disease, which demands care. The disease is caused when blood flow is prevented from reaching part of the brain. This can be as a result of inflammation or infection, which narrows the blood vessels that lead to the brain. Drugs such as cocaine and amphetamines also narrow the blood vessels in the brain and produce stroke (Merck Manual, 1999). Strokes usually damage only one side of the brain. Anatomically, the brain is structured in such a way that the nerves in the brain cross over to the other side of the body. When there is a sudden loss of brain function resulting from a disruption of the blood supply to a part of the brain, stroke occurs and because of the cross over of the nerves in the brain, symptoms appear on the side of the body opposite the damaged side of the brain (Brunner, 2004). Signs of stroke onset include sudden weakness or numbness in a particular part or side of the body. Stroke also causes sudden confusion, difficulty speaking, problems in visual acuity, or dizziness due to dysfunction in part of the brain. Neurological examinations, blood tests and other medical scans are used to diagnose a stroke. Through early diagnosis, stroke victims have a better chance of recovery and healing. While a stroke may vary in severity, they are among the top causes of death and adult disability developing countries. Strokes are sometimes called brain attacks because of the resulting brain dysfunction (Merck Manual 1999).

Stroke and its associated disability are on the rise in developing countries. It is projected to become the fifth-leading cause of disease burden by the year 2020 (www.earth.columbia 2006). Because of high risk for death, long-term disability and recurrence after stroke, prevention is key to reducing the public health impacts from cerebrovascular diseases. A report released at Columbia University's Earth Institute on April 26, 2004, suggests that heart disease and stroke are far more urgent threats to global health than commonly appreciated. They are causing hundreds of thousands of deaths each year in young people of productive age (www.earth.columbia 2006).

The impact of stroke is particularly devastating in rapidly developing societies. This is because the disease exacts a crippling toll on more vulnerable countries, hitting individuals and their families, propelling families into poverty, as young breadwinners and mothers die. Economically these breadwinners are also the most productive members of the workforce, and their efforts determine future prosperity and investment (World Health Organization 1990).

Stroke is one of the chronic conditions (Wiles, 1995). Education of the family members in management of stroke patients is very crucial since much of the care and management involves the relatives at home. Involvement of family caregivers is essential for optimal treatment of stroke patients in ensuring treatment compliance, continuity of care and social support. The diagnosis of stroke presents a major crisis not only to the patient, but also to the family. The families often assume the role of a caregiver under sudden and extreme circumstances, with minimal preparations and uneven guidance and support from the healthcare system.

Caring for a person with chronic illness is a demanding role. As care has shifted from hospital to the home, the role of the relatives has been transformed into a

complex, multifaceted responsibility that many are ill prepared to assume. This indicates that family is a very important aspect in every person's life especially in times of sickness. It is a basic unit in the structure of a human social organization. People should bear in mind that an individual's health that is wellness or illness affects the functions of the entire family (Stanhope, 2004).

Looking at the demand that is brought on the families, it is required that family members should be well prepared. The chronicity and disadvantages of stroke, plus the social and psychological impact the condition brings about, is crucial, hence there is need for people to also focus on the relatives' experience and knowledge on this condition.

1.3 STATEMENT OF THE PROBLEM

Since stroke is a chronic condition, the relatives of stroke patients do much of the care at home. The management of patients with stroke requires medical treatment to treat the underlying condition, which resulted to patient having stroke, and rehabilitation support, so that they should be able to cope with the situation. Thus the stroke patients are most of the times cared for at home by the relatives. Caring for a stroke patient at home poses significant challenges to the relatives. The relatives are affected socially and psychologically with the condition of their stroke patient. This is why it is very important to focus on the experience of relatives of these stroke patients.

1.4 SIGNIFICANCE OF THE STUDY.

The result of the study will benefit both the relatives of stroke patients and the care providers. The relatives of stroke patients will be provided with the correct and adequate information on stroke according to their needs and their knowledge deficits on the disease condition. The health workers will reinforce their health education on stroke and on how best to take care of a stroke patient. Thus the study will bring up issues that are critical on the care of stroke patients. The study will also prepare relatives of the stroke patients to effectively care for the patients.

1.5 OBJECTIVES

General Objective.

To assess the lived experiences of relatives of patients with stroke.

The aim of the study.

The aim of the study is to find out the knowledge and experiences of relatives of stroke patients in relation to stroke.

Specific Objectives.

1. To find out how the relatives perceive the condition (stroke)
2. To determine the roles and responsibilities that families play in taking care of stroke patients.
3. To explore the coping strategies that they employ to cope with the situation
4. To assess the assistance and support that families get from the health care system and their societies.

CHAPTER 2

2.0 LITERATURE REVIEW

Literature review helps to give information about the studies that were already done in relation to the topic under study (Polit and Hungler, 1991). The review consists of a critical evaluation of the literature obtained as a result of the search. It helps to identify the gaps in the studies done in which the current study will focus on. The main purpose is to presents a distilled and critical analysis of the relevant literature, showing how the study being reported is based on previous research and existing knowledge, and how the new work was intended to take that forward (Cormack, 1993). Thus it helps to gain a broad background or understanding of the information that is available related to the research problem of interest. For this study, the literature review will also focus on studies done elsewhere, on the experiences of carers of stroke patients.

Stroke is the third most common cause of death in industrialized countries and a major cause of adult disability. By 2020 stroke mortality will have almost doubled mainly as a result of an increase in the proportion of older people and the future effects of current smoking patterns in less developed countries (Ebrahim, 2001). However, the burden of caring for stroke survivors usually rests with family members who have neither chosen nor volunteered for the role of 'carer' .

There is growing recognition of the complexity of stoke recovery (Anderson, 1993). There are gaps in professionals' knowledge about patient' and caregivers' experience of stroke, and also relating to treatment and rehabilitation (Wolfe et al 1996). In addition, there are acknowledged problems in measuring the impact of health

services on stroke recovery. In much of the research on stroke recovery, the use of short-term, quantitative outcome measures has been dominant (Forster & Young, 1996). This partly reflects the fact that many health service interventions are short-term, concentrate on the early post-stroke period and emphasize physical function recovery. As life expectancy increases, rehabilitation is expected to become increasingly necessary to maintain the quality of life for older people (Laidler, 1994). There is also growing recognition of the need to widen the focus of rehabilitation to include not only physical but also affective and social dimensions of the recovery process. Foster & Young (1996) point to the multifaceted nature of stroke recovery and suggest that a comprehensive rehabilitation package is necessary in order for people to come to terms with the changes in their lives after stroke.

In his study of family carers of stroke survivors Brereto (2000) looked at 'Seeking': a key activity for new family carers of stroke survivors. The study involved 14 carers recruited from two hospitals in the north of England, one city hospital and one district general hospital serving a more rural area. The sample included six males and eight females whose ages ranged from 32 to 93 years of age. These family carers included 10 spouses, three daughters and one son of the stroke survivors. The overall aim of the study was to gain a better appreciation of the needs of new carers of stroke survivors and to consider how these needs change as their role develops. Data were collected using prospective serial in-depth, semi-structured interviews with the same informants every 2–3 months over a period of up to 18 months. Informants were purposively sampled from three areas: a general acute medical admission ward; a specialist stroke unit; and the community when stroke survivors did not enter hospital clinic.

Interviews were based on an initial interview guide, which was informed by the themes emerging from the initial seven interviews with experienced carers

(Brereton, 2000). Informants were invited to describe, in their own words, their needs relating to becoming a carer. The results of the analyses confirmed and elaborated upon the original four categories (`what is it all about?' `Going it alone', `Up to the job' and `what about me?') and identified `seeking' as the basic social process linking these themes. Seeking describes carers' efforts to better understand their role and to begin to establish some degree of `balance' within their new and often confusing situation. The results presented were related primarily to carers' seeking activities during their relatives' hospitalisation, up to the point of discharge. Differing forms of seeking activity were identified but `up to the job' emerged as the carers' primary concern, with the ultimate aim being to provide `best care' for their relative. In order to do this, carers engaged in multiple forms of `seeking' activity that served differing purposes.

The researcher concluded that professionals and family carers hare a common agenda, with both seeking to provide the `best care' to stroke survivors. Working in partnership offers the best way forward. This will mean that staff needs to be aware of, and respond to, the various forms of `seeking' behaviour. This is essential as carers are more likely to experience greater stress if they do not feel up to the job. Professionals therefore need to take an active part in preparing stroke carers, if stroke survivors are to get the `best care' possible.

Although this study was not about the experiences of relatives of stroke patients, it showed the importance of relatives because most of the carers were the relatives of the stroke patients.

Another research study was carried out by Smith et al (2004). The title of the study is 'Informal carers' experience of caring for stroke survivors'. The study aimed to

describe the experience of caring for a stroke survivor at one year after stroke in Scotland.

Semi-structured, taped interviews were conducted with 90 carers of stroke survivors one year after stroke. The interviews were part of a larger study, which included the administration of a range of valid and reliable multidimensional instruments to both carers and stroke survivors.

This was a two-year, descriptive study with retrospective and current data collected in 2000–2001. Each patient–carer 'pair' was visited at home once, one-year post stroke. The one-year timeframe was selected because: (1) the functional ability of most patient has stabilized by 12 months; (2) most rehabilitation has ceased by one year; and (3) carers would have been in the care giving role for some months. Patient inclusion criteria were: a World Health Organisation, (1990) diagnosis of stroke excluding subarachnoid haemorrhage; discharge from hospital 3–11 months previously; living in the community; and having an identified carer providing emotional, physical or social support. Patients were excluded if they were dependent on a carer prior to the index stroke; lived in a residential home; or had a terminal or psychiatric illness which in the researcher's judgement made study participation inappropriate.

In the end the researcher concluded that stroke aftercare is, in many respects, dependent on the carer and stroke survivor: they have the responsibility for their lives. However, in order to manage and exercise control, carers need to learn how to care and this requires that they have access to good quality stroke-specific information and education. However, alternative and innovative communication strategies [e.g. Internet-based] to facilitate and enhance carer and stroke survivor quality of life should be explored. Stroke follow-up requires new approaches and the

testing of other care models, including nurse-led initiatives, if quality of life is to maximized and further disability limited.

Dowswell et al (2000) carried out a research titled 'Investigating recovery from stroke'. The study aimed at providing more detailed description of the psychosocial difficulties associated with stroke. Thus the study used qualitative methods to examine the experience of patient and caregivers during the year of recovery after a stroke.

Semi-structured interviews with a purposively selected sample of 30 patient and 15 caregivers at the end of a randomised controlled trial 13–16 months post-stroke was used. Patients and caregivers provided vivid descriptions of the recovery process. Recovery was perceived in terms of the degree of congruence patients identified between their lives before, and after, stroke. Patients therefore had individual and personal yardsticks for measuring their recovery.

The results of the study showed a complicated picture of the difficulties faced by patient and caregivers in the year following stroke. There are significant difficulties in understanding what is meant by the terms 'adjustment' and 'recovery.

The study suggested that there is a need for a skilful and flexible service for both stroke patients and their caregivers. 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. Attention to these facets by both professional and research communities should result in both greater understanding and greater quality of care. There is a need to acknowledge that patients and their carers want and need a variety of services, which have to be finely tailored to meet individual needs as they arise.

Lawler et al (1999) carried out a different study titled recovering from stroke: a qualitative investigation of the role of goal setting in late stroke recovery. An intervention was designed to improve the psychosocial adjustment of patient and their caregivers during the first year after stroke. A subsequent qualitative study was conducted to examine the experience of patient and caregivers and the perspectives of specialist nurses, through structured interviews and through analysis of contemporary specialist nurse records. The records held details of goals for all patients. These written goals, together with data from interviews, provide a focus for examining the role of goal setting in the relationship between specialist nurse and patient/caregiver.

Data were collected from 30 patient and 15 caregivers using semi-structured interviews within 3 months of their final quantitative assessment (12 months after recruitment to the randomised trial). A purposive sampling frame was used to ensure that the subjects were broadly representative of the larger study population, in terms of stoke severity and specialist nurse.

The interview explored the impact of stroke and the services received. It also looked at the relatives' value to the patient/caregiver, and hopes and expectations for recovery.

Whilst 'goal setting' may be a recognized and established part of the nursing process, although accepted less comfortably by some nurses than others, the term is not in commonly amongst patient and caregivers (in relation to health problems generally and recovery from stroke in particular). An important element of the specialist nurses' role appears to be developing and maintaining motivation for the patient to take an active role in rehabilitation.

2.0 SUMMARY OF LITERATURE REVIEW.

It is estimated that 25-74% of stroke survivors require help with activities for daily living from informal caregivers, often family members (www.bmg.com). For the literature review, it indicates that although the physical, psychological, emotional, and social consequences of care giving and its economic benefit to society are well recognised, care givers' needs and experiences are often given low priority in the management of stroke. Interventions to support stroke care givers by providing education, counselling and emotional support is therefore important. This would improve the life of the stroke patients.

CHAPTER 3.

3.0 CONCEPTUAL FRAME WORK.

The General systems theory will be used in this study.

A system is a group of interrelated subsystems or parts that interact with one another in order to achieve a goal. The function of these interrelated parts determines the function of the whole system (Booyens 1999).

Creasia and Parker (1991) explained that the General systems theory is broad enough to include within it the prospective of the number of family theorists. General systems theory helps to focus on family characteristics and behaviour that influence family functions. A family is an open complex system. It includes interacting personalities composed of interrelated positions and roles (Whall et al 1983). A family is a living system in which there are a series of interlocking subsystems where a change in one part will produce a change in another. A family as any other type of system is composed of subsystems, which are interdependent. These subsystems in the family are family members. These subsystems function as one system. They also adopt each other and need to adapt to series of changes that might occur. Families are held together with unwritten but well understood regulations. These are for example, collection of norms, values traditions cultural practices and day-to-day expectations. The rules also depend on who forms part of the unwritten regulations (Grant, 1994). Individuals within the family are interdependent. A family as a system is homeostatic. Thus a change in one part of the subsystem will affect the whole system. Assumptions of the systems theory explain that family as a system changes contrary in response to stress and strains from within and outside (Lancaster and Stanhope, 2004).

Creasia and Parker (1991) explained that a family, like any other system includes the following elements; Input, output, throughput, feedback, boundary and environment. The input provides the system with resources. Thus it includes income, social support from friends and neighbours and also assistance from family members who are outside the defined family system. This helps to know how a family is run. Output in a family system focuses on observable behaviours, both short term and long term. Thus describing the behaviours seen rather than making conclusions about that behaviour which is being portrayed outside by the members in a family as a whole.

The family throughput mechanism focuses on set factors in the family characteristics, which predispose a family to behave in a particular way. These include social economic class, educational level, religion, family means of communication, decision-making patterns, family structures and roles. These influence the way a family works together.

A family boundary unlike an individual boundary is difficult to find (Creasia and Parker 1991). The boundary focuses on the factors that determine who is within the system of a family. It includes matter, energy and information that the system does not need. Therefore the family system formulates norms cultural beliefs, traditional practices and values.

The family's feedback mechanisms focus on how the family monitor its own functioning, and the kind of information and facts that the family accepts as evidence that it is meeting its goals. These are actually psychosocial measures. Goal accomplishment can be determined by external measures of success such as income and status, or it can be determined by internal measures basing on personal values.

Environment looks at the surrounding in which the family lives. An example is the community, and the resources that the community has provided to the family.

3.1 APPLICATION OF THE THEORY TO THIS STUDY.

This theory gives the relationship of relatives in a family hence it will help in showing the importance of relatives to stroke patients and the roles that they play in the management of individuals with stroke.

From the General systems perspectives, it is clear that if one member of the family is sick it affects the whole family. In this situation members of stroke patients are also affected by the illness of a relative. Stroke acts as a stressor in the families and will affect the equilibrium of the family (Creasier and Parker 1991). The families may react either by being maladaptive or adaptive in response to the illness. This will occur in order to reach homeostatic state. In addition to this, family as a system has norm, cultural practice and values that define its members and shows its uniqueness. These are the factors that influence the health seeking behaviours. In stroke patients, it will influence the type of medical help and rehabilitation that they will seek.

The general systems theory will act as a guide in carrying out this study since it talks about the relationship of members of the family in terms of subsystems. It will be used in analysing the findings. Understanding of the general systems theory will also provide the health practitioners with much knowledge on management of stroke patients since it gives an overview on how much the family members are involved in the well being of each other. Diagram 1, (Adopted from Clemen-Stone 2002) presents structural arrangements of a system in relation to family as a system.

DIAGRAM 1.

STRUCTURAL ARRANGEMENT OF A SYSTEM IN RELATION TO A FAMILY AS A SYSTEM.

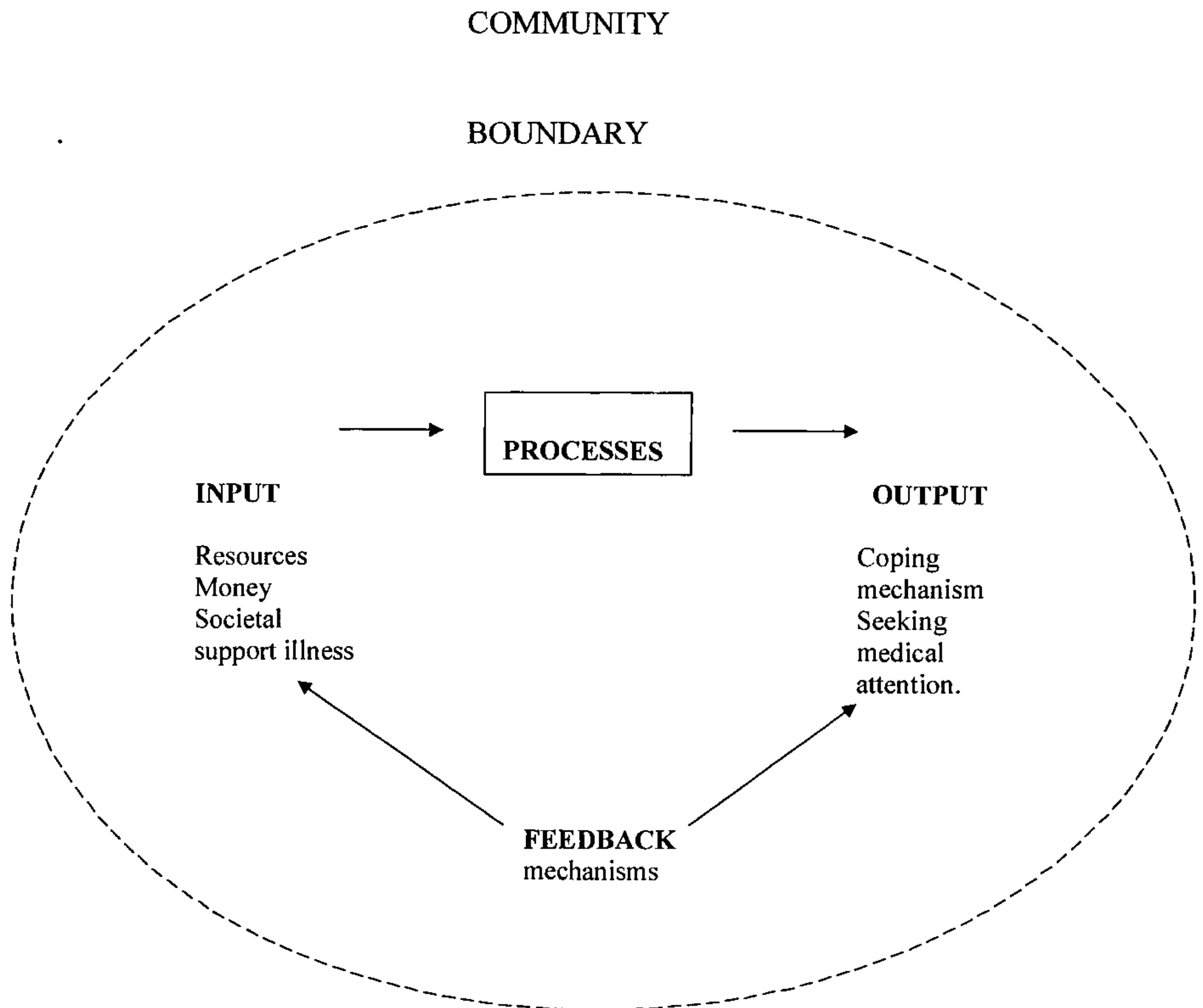

Fig 1. (Adopted from Clemen-Stone 2002).

CHAPTER 4

INTRODUCTION

This chapter is about the research methodology that will be used in this study. Thus it includes sampling method, setting, instruments to be used, data collection tools, data analysis, ethical consideration to be used in carrying out this study and plan for dissemination of the results of the study.

4.0 METHODOLOGY

The study design will be descriptive in nature. Descriptive study is a design of the study, which summarises the status phenomenon (Carpenter and Streubert, 1994). According to Polit and Hungler (1991) qualitative research describes the human experience as it is lived and defined by the actors themselves. Qualitative research method focuses on individuals' lived experiences as they are presented in thoughts, ideas, feelings, attitudes and perceptions. In addition, the research approach emphasizes human behaviour and social interaction. It explores the quality of a phenomenon (Carpenter and Streubert, 1994).

Qualitative research methods will be used during data collection and analysis of this study. This is to allow the researcher to collect adequate data to ensure adequate explanation of the problem (McCann, 1997).

4.1 SAMPLING.

The sample for this study will be selected from all the relatives who will bring stroke patients to physiotherapy and to hypertension clinic at Kamuzu Central Hospital. The subjects will be selected through purposeful sampling. Carpentry and Streubert (1994) state that purposive sampling can be the best in qualitative studies since the

researcher will be able to choose a group of participants who will be able to give adequate information concerning the phenomenon. Polit and Hungler (1991) state that this method involves the researcher hand picking the participants that he wants to be included in the study depending on the following characteristics age, level of education, tribe and religion. The sample will composed fifteen subjects.

4.2 SETTING

The study will be conducted at Kamuzu Central Hospital (KCH), which is a central hospital for the central region. KCH was chosen because of the rehabilitation services that the hospital provides to the stroke patients and it also provides a clinic for post stroke patients.

4.3 DATA COLLECTION INSTRUMENTS.

An interview guide, thus the questionnaire, will be used to collect data in order to obtain maximum information from the relatives. The guide will be composed of open-ended and close- ended questions. The questionnaire will be used as a guidance to interview the sample of fifteen relatives. These relatives will need to have qualities of true presentation of the population of relatives of patients with stroke.

4.4 PRE-TESTING

Pre-testing will be conducted at Kachere Rehabilitation Centre in Blantyre. This will be done in order to check if the questions on interview guide will be simple and clear for participants to understand. The pre-testing will also be done to ensure validity and reliability of the interview guide and also to estimate the approximate time the whole questionnaire will take to be answered. The pre-testing will be conducted on some relatives of stroke patients

4.5 DATA ANALYSIS.

Data analysis will be done manually. The open-ended questions in the qualitative data will be analysed through content analysis. According to Burns and Groves (1997), content analysis involves analysing a content of a narrative data to identify prominent themes and pattern among the themes.

4.6 ETHICAL CONSIDERATIONS

The permission will be sought first from Ministry of Health and Population and then at KCH as the study site of the research study. An individual consent will be sought from possible participants before they respond to the questionnaire. Polit and Hungler (1991) comment that potential subjects who are fully informed about the nature of the study, demands and the potential benefits are in the good position to make decision regarding their participation in the study.

4.7 PLAN FOR THE DISSEMINATION OF RESULTS.

The research findings will be communicated through a written report. Copies of the report will be presented at KCN library and another copy will be submitted at KCH. The research will also be presented to the medical and nursing forum, or get published in both nationally and internationally.

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Appendix 1

TIME TABLE FOR THE RESEARCH STUDY ON 'LIVED EXPERIENCE OF RELATIVES OF PATIENTS WITH STROKE.

ACTIVITY	MAY 2006	JUNE 2006	JULY 2006	AUGUST 2006	SEPTEMBER 2006	OCTOBER 2006	NOVEMBER 2006
Proposal writing							
Getting hospital clearance							
Pilot studying							
Collecting data							
Analysing data							
Report writing.							
Binding and handing in dissertation							

Appendix 2

BUDGET FOR RESEARCH STUDY ON 'LIVED EXPERIENCES OF RELATIVES OF PATIENTS WITH STROKE'.

ITEM	QUANTITY	COST IN KWACHA	AMOUNT
Diskette	4	K200.00	K800.00
Reams	3	K600.00	K1800.00
Pens	5	K10.00	K50.00
Pencils	2	K5.00	K10.00
Ruler	1	K50.00	K50.00
Envelopes	2	K20.00	K40.00
Photocopying questionnaires	20	K10.00	K200.00
Proposal binding	1	K500.00	K500.00
Dissertations binding	4	K500.00	K2000.00
Transport			K2000.00
Allowance			K1000.00
TOTAL			**K8450.00**

JUSTIFICATION OF PROPOSED BUDGET

The budget gives an overview of what facilities will be required and funds to cover items required in the course of the study.

STATIONERY

Enough stationary will be required for proposal development and dissertation. Plain papers will be required for typing, printing and photocopying. Envelopes will be used for posting clearance letters.

TRANSPORT

Funds will be needed for travelling to Blantyre and back for pre-testing.

SECRETARIAL SERVICES

Funds will be needed for photocopying and binding of research proposal and the final report.

ALLOWANCES

Funds will be needed for the upkeep of the principle investigator. Thus the funds will be used for food and accommodation.

QUESTIONNAIRE

SECTION A. DEMOGRAPHIC DATA.

1. Age of relative (tick)

   A. 11-20 ☐

   B. 21-30 ☐

   C. 31-40 ☐

   D. 40 and above ☐

2. Sex

   Relative (tick)

   A. Male ☐

   B. Female ☐

3. What is your Religion? (tick)

   A. Christian ☐

   B. Moslem ☐

   C. Pagan ☐

   D. Other (specify) ....

4. Relationship to the patient (tick)

A. Mother ☐

B. Father ☐

C. Brother ☐

D. Sister ☐

E. Other (specify)……………………..

5. Marital status of the relative (tick)

A. Single ☐

B. Married ☐

C. Divorced ☐

D. Separated ☐

E. Widowed ☐

6. What is your tribe (tribe)

A. Yao ☐

B. Chewa ☐

C. Ngoni ☐

D. Others (specify)..............................

7. How old is your patient

A. 1-5 years ☐

B. 6-12 years ☐

C. 12-25 years ☐

D. 26-40 years ☐

E. 40 years and above..............................

8. Sex of the patient (tick)

A. Male ☐

B. Female ☐

SECTION B. GENERAL EDUCATION.

9. How far did you go with education? (tick)

A. Did not go to school ☐

B. Primary school ☐

C. Secondary school ☐

D. University level ☐

10. How far did your patient go with education? (tick)

    A. Did not go to school ☐

    B. Primary school ☐

    C. Secondary school ☐

    D. University level ☐

SECTION C. OCCUPATION

11. Are you working? (tick)

    A. Yes ☐

    B. No ☐

12. If YES, what type of work?

    A. Farmer ☐

    B. Teacher ☐

    C. Others (specify)..............................

SECTION D. EXPERIENCE

13. What do you know about stroke?

....

....

14. What are the causes of stroke that you know?

....

....

15. What role do you play in the life of your stroke patient?

....

....

16. What are your cultural beliefs about the disease?

....

....

17. What problems does your stroke patient face in your community?

....

....

18. What problems do you face in your life, which are related to the fact that you have a stroke patient?.

....

19. How do you deal with the problems (if any)?

....

....

20. What assistance do you get from the health workers in relation to the management of your patient?

....

....

21. What is the improvement that you can see in your patient since you started bringing the patient to the hospital?

....

....

22. In what way is the community in which you live in, being supportive in care of your stroke patient?

....

....

23. What do you think the health workers should do in order to improve the management of these stroke patients?

....

....

CHICHEWA VERSION.

SECTION A. DEMOGRAPHIC DATA.

1. Muli ndi zaka zingati?

A. pakati pa 10-20 ☐
B. pakati pa 21-30 ☐
C. pakati pa 31-40 ☐
E. Kupyolera 40 ☐

2. Ndinu a amuna kapena a kazi

A. Amuna ☐
B. Akazi ☐

3. Ndinu a chipembedzo chanji?

A. Chikhirisitu ☐
B. Chisilamu ☐
C. Simupemphera ☐
D. Zina (tchulani)......................

4. Odwalayo ndindani wanu

A. Mayi ☐
B. Bambo ☐
C. Achimwene ☐
D. Achemwali ☐
E. Chibale china (tchulani)...........

5. Za Banja.

A. Simunakwatirepo/kwatiwepo ☐
B. Mulipabanja ☐
C. Banjalinatha ☐
D. Munapatukana ☐
E. Anamwalira ☐

6. Ndinu Mtundu wanji wa anthu?

A. Chewa ☐
B. Tumbuka ☐
C. Yao ☐
D. Lomwe ☐
E. Zina (tchulani)......................

7. Mbale wanu odwala ali ndi zaka zingati?

A. pakati pa 10-20 ☐
B. pakati pa 21-30 ☐
C. pakati pa 31-40 ☐
E. Kupyolera 40 ☐

8. Mbale wanu wodwala ndiwamwamuna kapena wankazi?

A. Amuna ☐
B Akazi ☐

SECTION B. EDUCATION.

9. Sukulu munalekezera pati?
   - A. Sindinapiteko ku sukulu ☐
   - B. Pulayimale ☐
   - C. Sekondale ☐
   - D. Koleji ☐

10. Mbale wanu odwala Sukulu analekezera pati?
    - A. Sanapiteko ku sukulu ☐
    - B. Pulayimale ☐
    - C. Sekondale ☐
    - D. Koleji ☐

SECTION C. OCCUPATION

11. Mumagwira ntchito?
    - A. Eya ☐
    - B. Ayi ☐

Ngati eya pitani kufunso (12)

12. Mumagwira ntchito yanji
    - A. Ulimi ☐
    - B. Uphunzitsi ☐
    - C. Zina (tchulani)................

SECTION D. EXPERIENCE.

13. Mukudziwapo chani za matenda okufa ziwalo (stroke)

....
....
....

14. Nanga matendawa amabwera bwanji?

....
....
....

15. Mumawathandiza bwanji abale anu amene akudwala matendawa?

....
....
....

16. Ndizikhulupiriro zanji zomwe mumakhulupirira ku mtundu wanu zokhuluzana ndi matenda okufa ziwaro.

....
....
....

17. Ndizovuta ziti zomwe mmbale wanu odwala matenda okufa ziwalo amakumana nazo kudera kwanu?

....
....
....

18. Ndizovuta zanji zomwe mumakumana nazo pamoyo wanu zokhuzana ndichifukwa chakuti muli ndi mmbale wanu wodwala matendaokufaziwalo?..

....

....

19. Nanga mumatani kuti muthane ndi mabvutowo (ngati alipo)

....

....

20. Ndi chithandizo chotani chomwe mumalandira kuchokera ku chipatala chokhuzana ndi kasamalidwe ka mmbale wanu odwala?

....

....

21. Pali kusintha kotani pa mbale wanu odwala chiyambireni kubwera naye kuchipatala.

....

....

22. Ndichithandizo chotani chimene mumalandira kuchokera kwa anthu a ndera lanu chokhuzana ndi kasamalidwe ka mbale wanu wodwala?

....

....

23. Mukuganiza kuti achipatala angakuthandizeni bwanji kupititsa patsogolo moyo wa mmbale wanu wodwala matenda okufa ziwalo?

....

....

....

....

Appendix 4

The University of Malawi,
Kamuzu College of nursing
Private Bag 1
Lilongwe.
16th June 2006.

The Director of Research,
Ministry of Health and Population,
Private Bag
Lilongwe.

Dear Sir,

REQUISITION FOR A NATIONAL CLEARANCE TO CONDUCT A RESEARCH STUDY ON 'LIVED EXPERIENCE OF RELATIVES OF PATIENTS WITH STROKE'

I am a fourth year student at Kamuzu College of Nursing. In order to complete my Bachelor of Science Degree in Nursing (Generic), I am required to carry out a research project. The title of my research is 'Lived experiences of relatives of patients with stroke'. The aim of the study is to find out about the knowledge and experiences of these relatives in relation to stroke. This will help to fill in the gaps that exist concerning management of stroke survivor patients, hence improving the lives of these stroke survivor patients. The research will be carried out from June to November 2006.

A signed informed consent will be sought from the participants before starting the interviews. The purpose of the study, method of collecting data and the benefits of the study will be told to the participants. The participants will be assured that the information obtained and their identity will be confidential. No participant will be forced to participate in this study.

The purpose of this letter is to ask for permission to carry out this study at physiotherapy department and hypertension clinic at Kamuzu Central Hospital in Lilongwe.

Your acceptance will be greatly appreciated.

Yours faithfully,

TAUNCIO NYIRENDA.

University of Malawi
Kamuzu College of Nursing
Private Bag 1
Lilongwe.
16 June 2006.

The Hospital Director,
Kamuzu Central Hospital,
P.O. Box 149,
Lilongwe.

Dear Sir/ Madam,

PERMISSION TO CARRY OUT A RESEARCH ON 'LIVED EXPERIENCES OF RELATIVES OF STROKE PATIENTS' AT PHYSIOTHERAPY DEPARTMENT/ CLINIC.

I am a fourth year student at Kamuzu College of Nursing. In order to complete my Bachelor of Science Degree in Nursing (Generic), I am required to carry out a research project. The title of my research is 'Lived experiences of relatives of patients with stroke'. The aim of the study is to find out about the knowledge and experiences of these relatives in relation to stroke. This will help to fill in the gap that exist concerning management of stroke survivor patients, hence improving the lives of these stroke survivor patients. The research will be carried out from June to November 2006.

A signed informed consent will be sought from the participants before starting the interviews. The purpose of the study, method of collecting data and the benefits of the study will be told to the participants. The participants will be assured that the information obtained and their identity will be confidential. No participant will be forced to participate in this study.

The purpose of this letter is to ask for permission to carry out this study at the physiotherapy department and the stroke clinic at your hospital. Your acceptance will be greatly appreciated.

Yours faithfully,

TAUNCIO NYIRENDA.

University of Malawi
Kamuzu College of Nursing
Private Bag 1
Lilongwe.
16 June 2006.

The Hospital Director,
Queen Elizabeth Central Hospital
P.O. Box
Blantyre.

Dear Sir/ Madam,

PERMISSION TO CARRY OUT A PRE-TESTING RESEARCH STUDY ON 'LIVED EXPERIENCES OF RELATIVES OF PATIENTS WITH STROKE .AT KACHERE REHABILITATION.

I am a fourth year student at Kamuzu College of Nursing. In order to complete my Bachelor of Science Degree in Nursing (Generic), I am required to carry out a research project. The title of my research is 'Lived experiences of relatives of patients with stroke'. The aim of the study is to find out about the knowledge and experiences of these relatives in relation to stroke. This will help to fill in the gap that exists concerning management of stroke survivor patients, hence improving the lives of these stroke survivor patients. The research will be carried out from June to November 2006, at Kamuzu Central Hospital, in Lilongwe.

The purpose of this letter is to ask for permission to carry out pre-testing study at Kachere rehabilitation. The pre-testing study will assist in checking if the questions on interview guide will be simple and clear for participants to understand. The pre-testing will also be done to ensure validity and reliability of the interview guide and also to estimate the approximate time the whole questionnaire will take to be answered. The pre-testing will be conducted on some relatives of stroke patients.

Your acceptance will be greatly appreciated.

Yours faithfully,

TAUNCIO NYIRENDA.

Appendix 5

INFORMED CONSENT FOR THE STUDY 'LIVED EXPERIENCE OF RELATIVES OF PATIENTS WITH STROK'.

I am a fourth year student, at Kamuzu College of Nursing. In order to complete my Bachelor of Science Degree in Nursing, there is a requirement to carry out a research study. The topic understudy is 'lived experience of relatives of patients with stroke'.

The result of the study shall assist the relatives, the patients and the health workers in improving the management of this condition.

The information you will give will be confidential and will only be accessible to the researcher and the supervisor. There are no risks attached to the study and there will be no personal benefits if you participate in this study.

I request you to respond to the questions in your best knowledge and understanding of the subject matter. Questionnaires will be destroyed after accomplishment of the study.

You are required to participate with your own free will and you are free to withdraw if you feel like doing so. If you are willing to take part in the study, please sign below.

I ....am willing to participate in the study after being fully informed about what the research is all about. I do understand that my participation in the study shall have no impact on the treatment my patient is receiving.

....

....

PARTICIPANT DATE.

....

....

RESEARCHER DATE.

INFORMED CONSENT IN CHICHEWA.

CHILOLEZO.

Ine ndine ophunzira za unamwino ku Kamuzu College of Nursing muno mu Lilongwe. Mwazina zofunikira kumalizitsa maphunziroanga ndi kupanga kafukufuku. Mutu wa kafukufuku yemwe ndikupanga ndi Zomwe amakumana nazo abale omwe amasamalila anthu odwala matenda oumitsa ziwalo (stroke) ku Kamuzu Sento.

Zotsatira za kafukufuyu zizathandiza abale oyang'anira wodwalawa kuti athe kuwasamalira bwino, ncholinga chopititsa patsogolo miyoyo ya anthu odwala matenda oumitsa ziwalo.

Muli kudziwitsidwa kuti simudzalandilapo cholowa mukalowa nawo mukafukufu ameneyu, koma mudzathandiza kupititsa patsogolo kasamalidwe kamatendawa.

Muli kukupemphedwa kuyankha mafunso malinga ndi mutu wa kafukufuku. Muli kutsimikilizidwa kuti mayankho anu onse azasungidwa mwachinsinsi, ndipo pamapeto a kafukufukuyi, zones zizawotchedwa.

Mulinso wololedwa kusiya kutenga mbali mukafukufuku ngati mufuna kutero.

Ine ....ndifuna kutengapo mbali mukafukufukuyu nditamvetsa bwino cholinga chake. Ndamvetsa kuti kutenga mbali kwanga kapena kulephera kutero, sikukhuzana ndi chithandizo chomwe ndimazalandira ndikulandirira mbale wanga odwala kuno ku chipatala.

....

....

WOTENGA MBALI MUKAFUKUFUKU TSIKU

....

....

OCHITA KAFUKUFUKU TSIKU