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LIST OF ABBREVIATIONS

CBoH	-	Central Board of Health
CHAZ	-	Churches Health Association of Zambia
CSO	-	Central Statistics Office
ITG	-	Integrated Technical Guidelines
MoH	-	Ministry of Health
SCD	-	Sickle Cell Disease
URTI	-	Upper Respiratory Tract Infection
UTH	-	University Teaching Hospital
ZDHS	-	Zambia Demographic Health Survey

DECLARATION

I here by declare that the work presented in this study for a Bachelors of Science in Nursing has not been presented wholly or in part for any other degree and is not being currently submitted for any other degree.

Signed...

Candidate

Approved..

lecturer

STATEMENT

I hereby certify that, this study is entirely the result of my own independent investigations. The various sources to which Iam indebted are clearly indicated in the text and in the references.

Signed...

Candidate

DEDICATION

This study is dedicated to my God the Lord Almighty, who gave me the strength to carry out the study

To my husband Mr. J. K. Sathumba Mukwato, who has proved to be a source of encouragement in my life.

To my son Thumba Mukwato, a blessing from God who endured without a mother at a tender age.

ABSTRACT

The main objective of this study was to determine the coping mechanisms of parents who have children with sickle cell disease. The specific objectives were: to determine the level of coping by parents whose children have sickle cell disease; to identify socio-cultural factors that influences coping with sickle cell disease; to identify factors in the health service delivery system that influences coping; to make recommendations to all concerned parties regarding changes to be made in improving the emotional and psychological support given to the parents; and to work with all concerned parties in hospital in developing a plan for implementing the recommendations.

The study was conducted at the sickle cell disease clinic of the University Teaching Hospital.

Literature review was based on global, regional and national perspectives of the coping mechanisms of parents who have children with sickle cell disease; the knowledge attitude and practice of care givers of children with sickle cell disease and the effect of sickle cell disease on the life of a sickler.

A descriptive, non-experimental quantitative research method was used. Data was collected from 50 parents whose children were below the age of 15 years. Respondents were chosen using simple random sampling using the rotary method. Questionnaires were used to collect data from the parents. Data analysis was done manually using a data master sheet and a scientific calculator.

The results from this study revealed that, parents use mainly long term coping mechanisms to cope with sickle cell disease in their families, which include seeking help from medical personnel (78%), praying to God for either healing or strength (20%) and giving medication (2%). However there are several factors which influence the way parents cope: level of education; level of knowledge on the disease; the number of sicklers they have; the social support they receive; their income; and their access to health services.

It was recommended that the management and staff of the University Teaching Hospital should come up with a formal teaching plan for parents to enable them to understand the disease; that health providers should advocate for the formation of a social support group for patients and their families; and that the hospital authority should have a provision to exempt children with sickle cell disease from cost sharing since this is a chronic illness.

CHAPTER ONE

1.0 INTRODUCTION

1.1 BACKGROUND INFORMATION

Zambia is a landlocked country situated in the central part of Africa within the Sub-Saharan region. It covers an area of 752,612 square kilometers (sq kms). It shares borders with the Democratic Republic of Congo and Tanzania in the north; Malawi and Mozambique in the east; Zimbabwe and Botswana in the south; Namibia in the south west and Angola in the west. Administratively the country is divided into 9 provinces and 72 districts (ZDHS, 2003). The total population of Zambia is 9,885,591 and consists of 4,939,293 females and 4,946,298 males. From the total population 45.3% are children aged 0-14 years (CSO, 2000). From the above figures, it clearly indicates that almost half of the Zambian population are children.

Health care in Zambia is provided by the Ministry of Health (MoH) through the Central Board of Health (CBoH), Churches Health Association of Zambia (CHAZ), the Private Health Practitioners and the Traditional Healers. Above 60% of the bed capacity is provided by the Government hospitals and health centres. 26% is provided by Mission Hospitals, 13% by Zambia Consolidated Copper Mines while 20% by private clinics (Ministry of Health, 1995).

In Lusaka District, health services are provided by the University Teaching Hospital (UTH) a third level hospital and the biggest hospital in the country. There is also one mental hospital in the country which is Chainama Hills Hospital. Other providers of health services are the 22 health centres under the Lusaka Urban District Health Management Team (LUDHMT),Mina Soko Military Hospital, as well as the several private clinics and Traditional Healers.

The Government of Zambia is committed to the fundamental and humane principle in the development of the health care system to provide Zambians with equity of access to cost effective quality health care as close to the family as possible. In order to facilitate the attainment of this vision, the Government has adopted the Primary Health Care (PHC) strategy as the most appropriate vehicle (MoH, National Health Policies and Strategies, 1991).

The objectives of the Primary Health Care are entrenched in its philosophy. The main objective was to address the main health problems such as:

- Promotion of health
- Prevention of ill-health
- Providing rehabilitative services
- Provision of curative health services

Primary health care concept has focused on many components, some of which are:

- Appropriate treatment of common diseases and injuries.
- Prevention of locally endemic diseases, because they contribute to loss of productivity and prevent people from reaching their full potential.

The above two concepts are important because, according to CBoH: ITG, (2002), about 75% of child mortality is due to preventable diseases/conditions such as malaria, diarrhea, pneumonia, anaemia and malnutrition.

In view of the above, the Government of Zambia through the Ministry of Health and its cooperating partners have paid a lot of attention in preventing and treating the leading causes of childhood morbidity and mortality. Unfortunately little attention has been paid to somewhat overt or concealed diseases which causes untold misery and suffering to its patients and their families, one of these being sickle cell disease (SCD).

It is not known exactly when, how or where the mutation producing the sickle cell gene occurred, but the sickle cell trait is found throughout tropical Africa including Madagascar, and it is also found in people of African descent in the United States of America, the Caribbean and South America where Africans were taken through involuntary migration from the sixteenth to the nineteenth century. The trait also occurs in Saudi Arabia, Central and Southern India, Ceylon, the Andaman Islands, the Mediterranean region including Sicily, Greece where nearly one in five people in the region posses the sickle cell trait. The gene has been found in white population outside the Mediterranean region as well, for example it is occasionally found in Great Britain, Canada and Australia. Other European countries such as Yugoslavia, Romania with Russia reporting 1.1% trait incidence (Konotey-Ahulu, F.I.D, 1992).

According to Ohene-Frempong, K. et al (1999) the prevalence (Percentage) of sickle cell trait in regions of Africa is as follows:

• North Africa	0.2 - 14.7%
• West Africa	1.7 - 30.7%
• Central Africa	0.6 - 27.0%
• Southern Africa	0.0 - 36.7%

From the above distribution, the highest incidence is found in West Africa followed by Central Africa.

In Zambia as in many African countries sickle cell anaemia, the most severe type of sickle cell disease is the commonest hereditary hemolytic anaemia. The average trait incidence is 15.26% with a range from 6.9% in the Southern Province to 30% in the Northern Province, Lwaba, C. M. (1988)

This condition persists through out life as a result, the patients and their families are faced with various socio-economic, emotional and developmental problems, with the socio-economic factor being the most important. According to Kanfwa, E. (1998) (unpublished study), the socio-economic status of the parents of a sickler appeared to be directly related to the number of crises.

In Zambia there has been no deliberate programme by the Ministry of Health which addresses the problem of sickle cell disease. As a result sickle cell disease patients and their families have not benefited from the national health resources as has been the case for other diseases such as malnutrition.

According to the Head of Department of Paediatrics and Child Health, School of Medicine, University of Zambia, the little attention paid to the disease is presumed to be the fact that sickle cell disease is not among the leading causes of childhood morbidity and mortality in Zambia. In addition the sickle cell disease association of Zambia which was established in 1986 has not been functioning for 10 years now. This leaves the newly diagnosed and old sickle cell disease patients with no source of support and health education. This makes it difficult for the parents to cope with the disease.

There is however a sickle cell disease clinic in the University Teaching Hospital which was established in 1973 and has been functioning to date. It is through this clinic that parents with children who have sickle cell disease obtain counselling, health education on the disease and medical care. Apart from the clinic, there is also a separate ward where these patients are admitted whenever they are ill. Occasionally nurses in this ward give health education to parents of children with sickle cell disease. With the above measures it is hoped that parents of children with sickle cell disease will receive the necessary counseling, health education and medical treatment.

Since there is no established sickle cell disease programme by the Ministry of Health and there is no sickle cell disease association, it is difficult to support these parents to adequately cope with the disease. In addition the cost sharing measures have put further strain on the parents as children with sickle cell disease are not exempted from paying medical fees despite the disease being chronic.

The attitude of the parents also plays a major part towards the ability to cope or not to cope with the condition. This is because the family members go through a series of stages during the crisis and it is during this period that they are supposed to appropriately employ coping mechanisms.

It is due to the foregoing reasons that it becomes imperative that we understand the coping mechanisms employed by parents of children with sickle cell disease amidst all the problems they may face.

1.2 STATEMENT OF THE PROBLEM

Sickle cell disease is a generic term applied to all disorders characterized by red blood cells containing an abnormal hemoglobin designated as sickle cell hemoglobin. The abnormality may be inherited as a homozygous (Hbss) sickle cell anaemia or heterozygous (HbAs) sickle cell trait. Sickle hemoglobin (Hbs) differs from normal hemoglobin (HbA) in having in each Beta chain an amino acid valine in the place of glutamic acid in the sixth position. In conditions where there is low oxygen tension this hemoglobin polymerises and forms cigar shaped bodies known as tactoids. Konotey-Ahulu (F.I.D, (1992).

The sickled red blood cells are responsible for the crises which cause suffering and numerous readmissions of these patients. The crises are characterized as follows:

(i) Obstruction of blood vessels by sickle red blood cells causing vaso-oclussive crises;

(ii) Pooling of blood in the spleen and lever – sequestration which reduce the hemoglobin concentration;

(iii) Maturation arrest of the bone marrow causing aplastic crises;

(iv) Massive destruction of red blood cells causing hemolytic crises.

Patients with sickle cell anaemia accounts for 2.92% of the total admissions at the Paediatric wing of the University Teaching Hospital (UTH), Lusaka, Zambia. It has the average case fatality of 6.61% of the total admissions, with the maximum mortality occurring in the age group one to five years (54.84%). The common causes of death being infections (29.54%). Vaso occlusive crises (22.72%) and spleenic sequestration crises (20.45%). The problems of sub-Saharan Africa like malaria, malnutrition and now HIV/AIDS add to the mortality (15.70%). The above statistics however are not representative of the severity of the problem as it is, as only referrals came up to the University Teaching Hospital with many more patients attended to at hospitals and clinics nearest to their homes, Chintu, C. (1995).

Sickle cell is a chronic, life threatening and disabling condition that affects the lives of not only the patients but the whole family. The management of sickle cell disease, therefore should involve the whole family. It is for this reason that it becomes imperative that parents who have children with the disease should employ certain coping mechanisms to be able to live with the condition and enjoy a relatively comfortable family life. Coping mechanisms have been defined by Lazarous, E. (1991) as "cognitive and behavioural efforts made to manage the specific external or internal demands that tax a person's resources". This entails that, an individual who applies positive coping mechanisms is better placed to cope with the condition than one who does not.

1.3 FACTORS CONTRIBUTING/INFLUENCING THE PROBLEM

There are several factors which may influence the coping mechanisms of parents who have children with sickle cell disease. These will be discussed as follows:

- **Access to Health Facilities**

  The ease with which parents can access health facilities will to a large extent determine the way they cope with a child with sickle cell disease. Access to health facilities is determined by several factors such as distance, user fees and waiting hours. Those parents who stay near health facilities, are be able to pay user fees and are attended to within the shortest possible time at health facilities are better placed to cope with the disease. On the other hand, parents who stay far away from health facilities, are not able to pay user fees and wait for long hours before they are attended to may not find it easy to cope with the disease.

- **Social Support System**

  Those parents who receive less or no support at all from their relatives, the church and the community at large may find it difficult to cope with a child with sickle cell disease, as compared to those who receive support from the extended family, the church and the community.

  Those who have social support system in place for example, may be able to take their children to hospital for any illness including crises. The same people will visit them while in hospital and give them support to augment the care and support from family members.

- **Knowledge about the disease**

  Those parents who have the correct knowledge about the transmission of the condition and the prevention of painful crises may find it easy to cope with the disease as compared to those who have inadequate or incorrect knowledge about the disease. Those parents who know what the condition is and what it involves may be more likely to cope and cooperate in the care of the child. In regard to those without such facts, they may blame each other for the child's condition resulting in marital disharmony and even divorce.

The knowledge about the disease depends on several factors, for example the level of education and access to both print and electronic media. Those who have undergone formal education are able to read and write, as a result they may read magazines about people who have lived for several years with the condition and living a relatively normal life. They may also read about ways of preventing crises. This will in turn help them to have knowledge on the prevention of crises and to hope for the better for their child. As for the illiterate, they may have limited knowledge on the precipitating factors to crises and chances of misinformation are high. This in turn will determine the way the two groups cope. The parents who can access the information may adopt positive attitude than those who are misinformed.

- **Past Experience**

Past experience could either be positive or negative. Those parents who could have had a positive past experience, for example having another child or a relative with the disease and is living a normal life might cope well with the disease. In regard to those who could have lost a child or relative at an early age might have a lot of fears and this may affect the way they cope. Past experience could be about the way parents were treated by health care providers. If health care providers were caring and supporting, the parents may find it easy to seek health services. Health education received in the past may also influence the way one copes with a chronic condition. Those parents who could have received health education on the care of the child at home and the prevention of crises may cope better than parents of newly diagnosed sicklers.

- **Service Delivery Factors**

There are several service delivery factors that may influence the way parents cope with the condition. The training that health care providers receive to care for the patients and the levels of staffing and supervision will determine the quality of care given to the patients especially during painful crises. Inadequate health education during hospitalization may prevent parents from adhering to medical advice resulting in difficulties in coping with the condition. The non-availability of material resources and equipment at health centres and hospitals may discourage parents from seeking health services when their children have minor illnesses ending into complications. The negative attitudes of health care providers may also hinder certain individuals from seeking health services.

- **Socio-economic status of the Parents**

The socioeconomic status of the parents depends on their level of education and the type of occupation. Those parents from high socio-economic class may cope better than their poor counterparts. The rich and educated are able to afford user fees, have access to information through print and electronic media. They are also able to afford good housing water and sanitation with good food to prevent minor infections which are common precipitants of crises. As Konotey-Ahulu, F.I.D. (1992) puts it "speaking generally, in Africa patients whose socioeconomic background allows them to be protected against infections and infestations do best living almost normal lives".

- **Socio-Cultural Factors**

i. Age

The older women may be more likely to have knowledge and experience on the care of children especially if they have another child with sickle cell disease. When this is the case, they will be more willing to employ coping mechanisms which will help their children. In the case of younger women, they have no experience on the care of children, together with the added burden of repeated hospitalization, they may find it very difficult to cope with the condition.

ii. Marital Status

Married couples are more likely to support each other in taking care of the child with sickle cell disease

As for the single mother she may be the only one to take care of the child as a result she may get stressed and find it burdensome to live with such a child.

iii. Health Status of the Parents

The parents of sicklers are carriers of the sickle cell trait, although they may not go into crises, their health in most cases is not as good as normal individuals. This is made worse if they have another condition such as HIV/AIDS. The parent's health therefore may influence the way they cope with a sickler.

IV. Beliefs

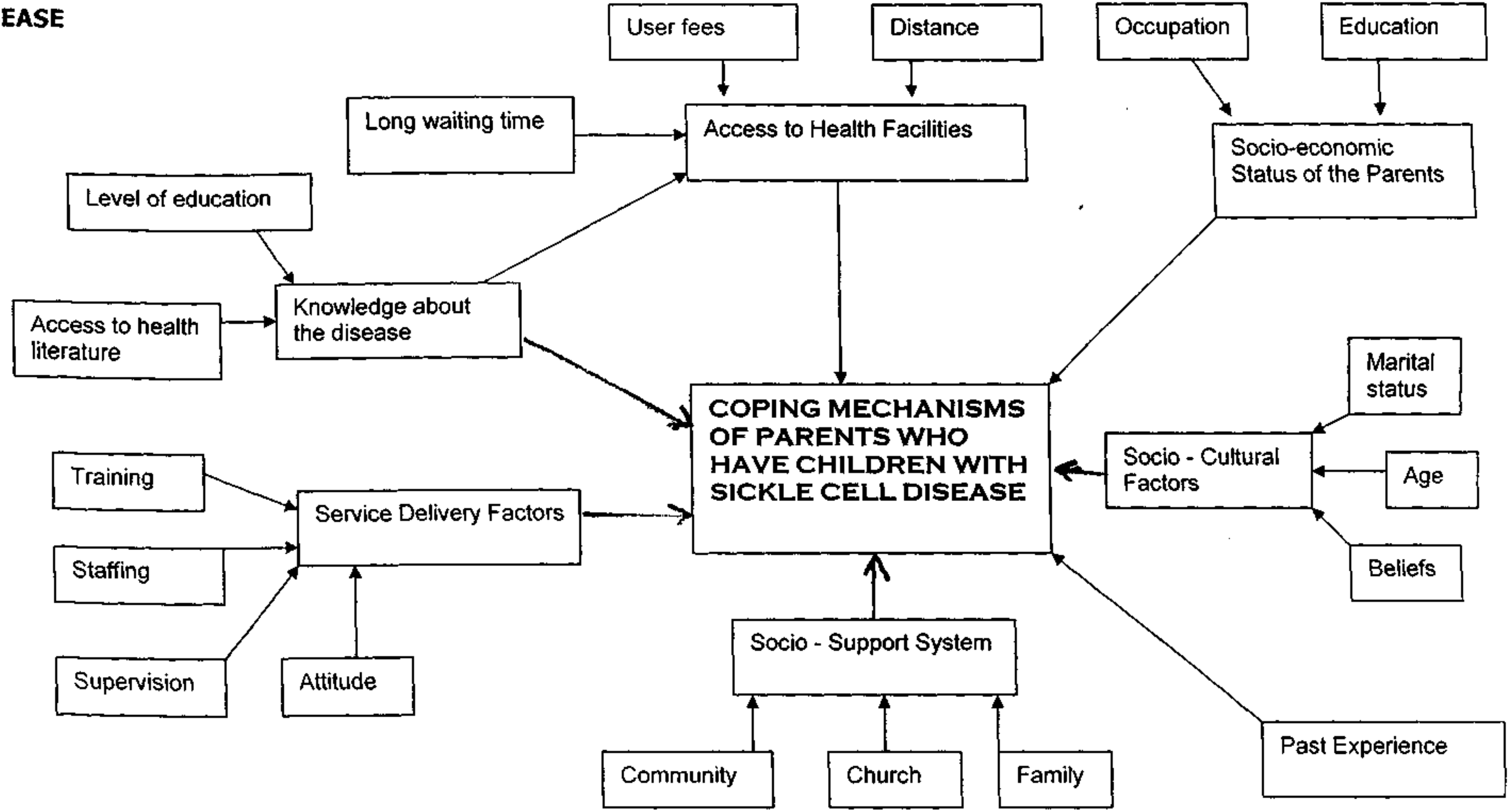
Beliefs regarding the cause of the condition may influence the way parents cope. If parents believe that the child has been bewitched they may not comply with medical advice as a result they will always blame somebody for their child's fate.

V. level of Education

Parents who are illiterate might find it difficulty to comprehend the health information on the cause, course and the preventive measure required to keep the condition under control. This in turn may influence the way they cope with the disease. In regard to the literate parents, their level of understanding and comprehension of information may be better. This may enhance their compliance to medical advice and cope positively in living with a sickler.

1.4 PROBLEM ANALYSIS DIAGRAM

FACTORS THAT MAY INFLUENCE COPING MECHANISMS OF PARENTS WHO HAVE CHILDREN WITH SICKLE CELL DISEASE



1.5 JUSTIFICATION

The information on coping mechanisms of parents whose children have sickle cell disease is almost non-existent in Zambia. Most of the information available on sickle cell disease is on the knowledge, attitude and practice of caregivers. While information on knowledge, attitude and practice is important, literature on coping mechanisms used by parents whose children have sickle cell disease could be more vital since the condition is a life long condition. For the family, there is nothing more heart breaking than watch their child endure extreme pain and life threatening medical conditions. The patient endures, not only the pain itself but also the emotional strain from unpredictable bouts of pain, fear of death and social isolation.

It is for this reason that, this study was designed to determine the coping mechanisms used by parents whose children have sickle cell disease. The findings will help the health care providers to come up with a teaching plan that covers all the aspects of the disease so that more emphasis is put on those areas where need is greatest. This will in turn enhance the parents' understanding of the disease and clear some misconceptions.

It is also hoped that the data generated will help health care providers to be more compassionate because it is very important for patients and their families to find emotional and psychological support especially in times of a crises. Families need to be supported because no one should or can endure this life –long disease alone.

1.6 RESEARCH OBJECTIVES

The following are the objectives for this research.

1.6.1 General Objective

To identify and describe factors influencing the coping mechanisms of parents whose children have sickle cell disease.

1.6.2 Specific Objectives

1.6.2.1 To determine the level of coping by parents whose children have sickle cell disease;

1.6.2.2 To identify socio-cultural factors that influences coping with sickle cell disease;

1.6.2.3 To identify factors in the health service delivery system that influences the parents' coping with the disease;

1.6.2.4 To make recommendations to all concerned parties in health institutions regarding changes to be made in improving the emotional and psychological support given to the parents;

1.6.2.5 To work with all concerned parties in Hospital in developing a plan for implementing the recommendations.

1.7 HYPOTHESES

The following hypotheses specify the expected relationship among variables.

1.7.1 The parents with high levels of education cope better with sickle cell disease than those with low level of education;

1.7.2 The higher the socio-support given to parents by the extended family, the church and the community, the better the ability to cope;

1.7.3 Poor access to health facilities due to long distance, user fees and long waiting hours lead to poor ability to cope with the condition;

1.8 OPERATIONAL DEFINITION OF TERMS

An operational definition is the researcher's definition of a term that provides a description of the method for studying the concept by citing the necessary operations" Dempsey, P. A., and Dempsey, D. A., (2000).

The following are therefore the terms which will often be referred to in this study:

1.8.1 Sickle Cell Disease

It is a term applied to all disorders characterized by red blood cells containing an abnormal hemoglobin known as sickle hemoglobin.

1.8.2 Sickler

Any individual who has the sickle cell disease.

1.8.3 Parent

Any individual who has a child i.e father or mother.

1.8.4 Coping Mechanisms

These are conscious or unconscious strategies used by an individual to deal effectively with or to manage a situation.

1.8.5 Repeated Admission

Having been admitted to the hospital (UTH) more than once in 12 months.

1.8.6 Child/Children

Minor/Minors below the age of 15 years.

1.8.7 Crises

Painful episodes experienced by the patient when sickled blood cells block oxygen flow to the tissues.

1.9 VARIABLES AND CUT OFF POINTS

VARIABLES	**CUT OFF POINTS**	**INDICATORS**
INDEPENDENT VARIABLES		
Knowledge	High	Ability to answer questions correctly that sickle cell disease is a hereditary and life threatening condition which though cannot be treated, it can be controlled. scores 5 points.
	Medium	Respondent gives a vague explanation of what sickle cell disease is and how it is transmitted and has some information on the control mechanisms. Scores 3-4 points.
	Low	Respondent does not know how sickle cell disease is transmitted or does not know how the condition comes about and its management. Scores 0-2 points
Level of education	High	Tertiary education
	Medium	Secondary education
	Low	None or primary education
DEPENDENT VARIABLE		
coping	Very well	Respondent understands how the condition is transmitted, accepts it as a life long condition and employs certain measures to prevent painful crises thus reducing readmissions and allowing the child to live a normal life within the limits of the condition. Scores 11-15 points.
	Well	Respondent gives a vague explanation of how sickle cell disease is transmitted and employees a few mechanisms to prevent painful crisis which reduces the number of admissions. Scores 6-10 points
	Poorly	Respondent does not know how the condition is transmitted or controlled thus she/he takes no measures to prevent painful crises as a result his/her child has repeated admissions. Scores 0-5 points.

0

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 INTRODUCTION

There is hardly any literature on the coping mechanisms of parents whose children have sickle cell disease. However, there is literature on the knowledge, attitude and practices of patient caregivers most of whom are parents. There is also literature on the common problems experienced by sicklers and on the lifestyle measures that can help in managing sickle cell diseases. Most importantly there is some literature on the coping mechanisms of parents whose children have chronic conditions under which sickle cell disease falls. Therefore this review is aimed at determining what is already known about the topic and to identify gaps in the existing literature.

2.2. GLOBAL PERSPECTIVE

Sickle cell anaemia affects millions of people throughout the world. It is particularly common among people whose ancestors came from sub-Saharan Africa, Spanish speaking regions (South America, Cuba, Central America); Saudi Arabia, India and Mediterranean countries such as Turkey, Greece and Italy. In the United States, it affects around 72,000 people, most of whose ancestors come from Africa. The disease occurs in about 1 in every 500 African-American births and 1 in every 1,000 to 1,400 Hispanic-Americans or 1 in 12 African-American carry the sickle cell trait, http://www.ornl.gov/TechREsources/Human-Genome/posters/chromosomes/sca.html.

In a 1997 study on new born screening of sickle cell disease(author is not given) reported that the mortality rate for Africa –American children with sickle cell disease has reduced by up to 53%, perhaps due to preventive treatment with penicillin, new born screening, aggressive research and improved medical care. Currently, about half of the sickle cell patients in

America live beyond 50 years. The increase in the life expectancy of the African-American with sickle cell disease has been attributed to new born screening for the disease.

According to the Agency for Health Care Policy and research (1993), new born screening for sickle cell disease was instituted in 44 of the 50 states of the United States. This was after the 1987 consensus development conference on the subject. The reason for detecting sickle cell disease at birth is primarily to enable initiation of penicillin prophylaxis at an early age in order to reduce the incidence and mortality from pneumococcal sepsis. In addition, early detection affords sickle cell disease programmes the opportunity to educate families about early recognition of the signs and symptoms of the disease.

One in every 4,000 children in the United States is born with sickle cell disease as compared to one in every 50 Ghanaian babies. While 95% of those American children live past the age of 20, only 5% of the Ghanaians live to see their fifth birthday. The reason for this is said to be lack of timely diagnosis, lack of knowledge on the disease and even where knowledge exists, facilities and resources are not adequate. This entails that, while the children born in the United States are fortunate enough because advanced treatment is available for the disease, for children in African the prognosis is bleaker. Although the disease is the same in America and Africa, but the environmental differences between America and Africa means that it has a much worse effect on Africans. Ohene-Fromponge, K (1995).

2.3 REGIONAL PERSPECTIVE

Africa accounts for majority of sickle cell disease patients worldwide. About 40% of people in certain parts of Africa have the trait as compared to 9% of African-Americans having the trait
http://wellness.uedavis.ed/medcal_conditionsza/sicklecell-58.html.

The scientific study of SCD, its prevalence and its distribution in Africa quickly established a higher gene frequency in Africa than America and higher frequency in low-lying, rainy areas than in highlands and arid regions of the continent. Surveys throughout Africa since the 1950s have established ethnic and regional distribution of the sickle and related globin genes. Traditionally, the distribution of sickling disorders in Africa followed the pattern of geographic conditions and agricultural practices that supported the breeding of mosquitoes the carrier of the malaria parasite. The highest frequency of the sickle gene is found in west, central and east African countries, and especially in the low lying wet regions.

Relatively lower frequencies are found in populations living in cooler, dry highland areas where mosquitoes do not breed as easily ie in north and South Africa. Ohene-Frempong (1998).

The higher incidence of sickle cell gene in malaria endemic areas is due to its ability to make red blood cells resistant to the malaria parasite. http://wellness.ucdavis.ed/medical conditionsaz/sicklecell-58html.

There is abundant scientific knowledge about sickle cell disease. The National Institute of Health (NIH) calls it the best studied disease of man, yet less progress has been made towards a cure than for other genetic diseases, a situation Ohene-Frempong said is partly due to whom it affects and where it is most prevalent. Ohene-Frempong, K (1998).

In the United States, the management of sickle cell disease has become fully integrated in the public health service. In Africa sickle cell disease is not a priority as a public health problem. The impact of the disease on public health in Africa is largely unknown to African and International Health Agencies. Even in the "endemic" areas of west and Central Africa, most Ministries of Health have no programmes dealing with the disease. No statistics on the morbidity and mortality are available in most Africa countries.

In the absence of reliable epidemiological data, reported mortality rates often came from hospital-based sources with relatively small numbers of patients which do not represent the majority of the patients in the community. Moreover, many deaths (particularly those of young children) are not reported in many African countries. Without prior diagnosis and without death reports, hospital based mortality rates probably represent only the tip of the iceberg. America society for hematology, (1999).

From the above report, it becomes evident that patients with sickle cell disease in Africa do not receive adequate support due to lack of coordinated programmes by several ministries of health within the region. In assessing how serious the disease is, no one should under estimate the emotional and social impact of the disease. These patients undergo frequent hospitalization. The financial costs of medical treatment combined with lost school and work hours can be very burdensome. Although all chronic illnesses places stress on the patient and family, it is worse for sickle cell patients and caregivers who often face great obstacles in finding psychological support for the disease.

Communities, in which many sickle cell disease patients live, generally lack services that can meet their needs, and professionals who work in their medical facilities are often overworked. In a study comparing patients with different kinds of long term illnesses, those with sickle cell disease gave the lowest score to their physicians and other professional caregivers for compassion and satisfaction with medical care. http://wellness.ucdavis-edu/medicalconditions-az/sicklecell-58.html.

2.4 NATIONAL PERSPECTIVE

In Zambia as in many African countries, sickle cell anaemia the most severe form of sickle cell disease is the commonest hereditary hemolytic anaemia. The average trait incidence is 15.26% with the range from 6-9% in the Southern Province to 30% in the Northern Province. Hemoglobin C (Hbc) and

Beta Thalassemia have not been reported so far among indigenous Zambia, Lwaba, C. (1998).

According to the Head of Department of Paediatrics and Child Health, School of Medicine, Lusaka, Zambia, sickle cell distribution in Zambia is such that it is lowest in the Southern Province and it increases as you go towards the Northern Province. This distribution is said to follow the severity of malaria endemicity which is lowest in the Southern Province. The high incidence of sickle cell anaemia in malaria endemic areas has been attributed to the fact that malaria parasites might find the erythrocytes of sicklers a less favourable environment than normal cells. This explains why the heterozygous sicklers might have a greater resistance to malaria than normal homozygotes. Thus the heterogygous sickler has a better chance of survival to adult life as he/she is protected from severe forms of malaria attacks in childhood. This entails that such a surviving heterozygous sickler has a chance of marrying another heterozygous sickler to produce more and more sicklers thus increasing the incidence of disease. This argument is supported by Lulu, A. L. Nuaim, (1997) on the study of malaria endemicity in central Africa which revealed that in all areas that have a past or present history of malaria endemicity the Hbs gene frequency is high while all the non-malaria endemic regions have a much lower frequency.

In a study conducted by Kanfwa, E (1998) (unpublished study) on the effect of sickle cell disease on the life of the sickler in UTH the author says, sickle cell anaemia is one of the common causes of paediatrics admissions. It is also one of the common anaemias seen at the University Teaching Hospital and a common cause of readmissions among the paediatrics. In a later study conducted by Matabile, J. (2002) on the knowledge, attitude, and practices of the patient caregivers at UTH, it was found that on average, every 6 months a sickle cell disease patient is readmitted to hospital.

The common causes of these readmissions are crises. The crises start after 6 months and as the sickler grows older the frequency reduces to approximately 1 in 6 months to 1 in 2-4 years. The severity of the crises also diminishes. Tragic deaths however occur frequently from infections. In his study Matabile, J. concluded that 72% of the respondents said the crises which caused admissions were brought in by infections, mostly malaria and upper respiratory tract infections (URTI). This is very important in that, with the right information they will be able to prevent the crises by giving prophylactic antimalarials and intervention measures tailored at tackling URTI. This then can be the starting point for positive coping because, once the crises are reduced, the re-admissions will consequently reduce thus reducing the financial, time and work pressures on the parents.

The readmissions are very costly to the patient and family and the health care system too. The patient looses a lot of school time as most of his/her time is either spent in hospital or convalescing at home. For the family they spend a lot of money on the sickler in ensuring that the patient is well fed, well clothed and has a constant supply of medicines such as antimalarials and iron tablets. Those families that live far away from the hospital, a lot of money is spent on traveling. Many mothers of sicklers have to give up employment to look after the children as they have to be on the child's bedside. Kanfwa, E. (1998).

In a clinical and postmorterm study of fatalities due to sickle cell anaemia by G. P.T. Barclay (1970), he concluded that there was a high correlation between fatal outcome and poor treatment and follow up record. It is tempting to suggest that treatment is beneficial but probably of greater significance is the attention given by the mother to her sickle cell child. The mother's role may also account for the high incidence of first born and only child among fatalities. Nearly a third of those fatal cases were first born children, where as among the survivors only 19% were first born. It gives an impression that the older more experienced mother who already has a family before the arrival of the homozygous sickler is better able to look after her sickle cell anaemia child in his or her first two critical years.

The sicklers and their families face other pressures resulting from their disease process. Sickle cell disease affects the life of the sickler in many ways. The nature of the disease is such that, it involves all aspects of the sickler's life, that is mental, physical, social and economical. In the study of 80 sicklers at UTH, Lusaka, Kanfwa,E. as stated earlier concluded that the weights of the sicklers were found to be below the weight of normal children of their age. The onset of menarche in female sicklers was delayed by 2 ½ years. Because of the delay in onset of puberty in sicklers, there is late manifestations of secondary sexual characteristics. When all boys have experienced facial hairs, voice changes, the sickler still looks young. Similarly female sicklers may not have any feminization features or change on her body until much later.

The delay in the onset of puberty brings significant stigmatization with consequent pressures on both the patient and family. However, despite the pressures these families face, the study by Kanfwa, E., indicated that there are some families which inspite of having a sickler they continue producing more children ending up with 4 or more children with sickle cell disease. With the reasoning that parents fear that death will inevitably result in their sickle cell disease children so they keep having more hoping some will be normal. Parents would be reassured if more and more sicklers were able to survive and cope adequately in society.

There are two main forms of coping mechanisms employed by people undergoing stressful situations. These are long-term coping mechanisms and short –term mechanisms. In a study by Sakwimba, L.C.K, (1987) to determine the coping mechanisms of parents who have children with sickle cell disease, he stated that in order to cope 46% of parents prayed to God For God to either heal their child or give them strength to pull through the crisis.

40% cried, 8% went to see a witchdoctor to find the cause of the illness, 4% talked it out to other people in form of complaining while the other 2% sought comfort from significant others. While short term coping can reduce stress to a tolerable limit temporarily, but in a long run are ineffective ways to deal with stress and reality. Thus the need for long term coping mechanisms such as change in lifestyle. Kozier, B., et al (2000).

There are several factors which influence the effectiveness of coping by individuals such as:

- Number, duration and intensity of the stressor;
- Past experience of the individual;
- Support system available to the individuals;
- Personal qualities of the person.

If the duration of the stressors is extended beyond the coping powers of the individual, that person becomes exhausted and may develop increased, susceptibility to health problems. This is seen in family members who undertake the care of a sick person in a home for a long period. This stress is called caregiver burden and produce responses such as chronic fatigue, sleeping difficulties and can also result in mental illness. Schafer, W., (1992). It is for these reasons that parents who take care of children with chronic diseases of which sickle cell disease is one of them, should be supported so as to help them adopt long-term effective coping mechanisms which can result in adaptation as opposed to ineffective coping mechanism which can result in maladaptation. Nurses need to remember that although coping behaviour may not always seem appropriate it is always purposeful and should be supported.

2.5 SUMMARY

A review of the literature has shown that not many studies have been carried out on the coping mechanisms of parents who have children with sickle cell disease. However, from the available literature it has been realized that parents use many mechanisms which include among others, praying to God, crying, and complaining to others or seeking comfort from significant others. These mechanisms are very important because they help these parents to adapt to the situation.

Literature has also reviewed that the care and support given to the parents is a determining factor towards the parent's coping. As it has been shown that those parents who live in areas where support is available and there is advanced treatment of the disease, they are better placed to cope than those who live in areas where such services are lacking.

CHAPTER THREE

3.0 METHODOLOGY

This research study is aimed at determining the coping mechanisms of parents who have children with sickle cell disease.

3.1 RESEARCH DESIGN

Research design is defined as "the overall plan for addressing a research question including specifications for enhancing the integrity of the study", Polit, D. F., and Hungler, B. A., (2000). For the purpose of this study a descriptive, non-experimental quantitative research method was used.

A descriptive research is defined as a non-experimental research design to discover new meaning and provide new knowledge when there is very little known about a phenomenon of interest. Dempsey, A. P. and Dempsey, A. D. (2000). This type of design was chosen because it describes phenomenon and allows data collection to show the association between the dependent and independent variables. The other reason is that the questions in the questionnaire involved asking subjects to describe how they cope with sickle cell disease.

A quantitative design is defined as, "a method in which the study variables are pre-selected and defined by the investigator and data are collected and quantified, then statically analyzed often with a view to establishing cause-effect relationship among variables", Dempsey, A. P. and Dempsey, A. D, (2000).

This research study is a quantitative study because the answers or the findings of the study were categorized and quantified in numerical form.

3.2 RESEACH SETTING

This study was conducted at the University Teaching Hospital which is the largest hospital in Zambia. The hospital caters for the Lusaka population and is a referral centre for all patients from other hospitals in the country requiring speciality care.

The study was conducted in the sickle cell disease clinic, which is located in clinic 6 of the University Teaching Hospital. The sickle cell disease clinic was chosen because it has subjects with similar characteristics which is the criteria of the study.

3.3 STUDY POPULATION

A study population is defined as, "the total group of individual people or things meeting the criteria of interest to the researcher", Dempsey, A. P. and Dempsey, A. D., (2000).

The target group for this research study were parents who have children with sickle cell disease, below the age of 15 years who were being reviewed at the sickle cell disease clinic of the University Teaching Hospital. Only those children with Hbss were included.

3.4 SAMPLE SELECTION

Sample selection is defined as, "the process of selecting a portion of the population to represent the entire population", Treece, E. W. and Treece, J. W., (1986). For the purpose of this study and to ensure that a representative sample is selected, a simple random sampling with replacement technique was used. The 50 respondents were chosen using simple random sampling using the lottery method. Simple random sampling with replacement was used in order for the respondents to have an equal and independent chance of being selected each time. Numbers were written from 1 up to 100. Participants were asked to pick a number from the bag. All those who picked odd numbers were then interviewed using an interview schedule. The investigator interviewed at least 10 respondents for at least 30 minutes each day for 5 clinic days which are on Fridays. The interviews were conducted after the clinic reviews.

3.5 SAMPLE SIZE

A sample size is defined as, "the number of subjects in a sample", Polit, D. F., and Hungler, B. P, (1997). A sample of 50 respondents was chosen for this study. It was decided to have a sample of fifty (50) respondents because of the limited time in which the study was conducted and submitted in partial fulfillment of the B.Sc. degree in nursing.

3.6 DATA COLLECTION TOOL

Data collection is defined as, "the gathering of information needed to address a research problem", Polit, D. F., and Hungler, B. P., (1995). For the purpose of the study, a semi-structured interview schedule was used to collect data.

"An interview schedule is a formal instrument used in structured self report studies, that specifies the working of all questions to be asked of respondents", Polit, D. F., and Hungler, B. P (1997). A face to face interview using a questionnaire method was used.

This method was chosen because it allows information to be obtained from both the literate and illiterate respondents. It also permits anonymity resulting in more honest answers.

3.6.1 VALIDITY

Validity is defined as, "the degree to which an instrument measure what it is intended to measure", Polit, D. F. and Hungler, B. P., (1997).

Validity was upheld by ensuring that the same questions are asked to each respondent in the same sequence. The questionnaire was clearly constructed to avoid ambiguity.

3.6.2 RELIABILITY

Reliability is the stability of a measuring instrument over time, concerned with consistency, stability and repeatability of the informants` accounts as well as the investigating ability to collect and record information accurately:, Blink, H. I., (1996).

3.7 DATA COLLECTION TECHNIQUE

Permission to collect data was obtained from the Director of the University Teaching Hospital, the Nursing Services Manager, the Head of Paediatrics and Child health and also from the Nursing Officer for Paediatrics and the sister in charge for Haemato-oncology ward and sickle cell disease clinic.

An interview schedule was used to collect data from mothers of sicklers who were being reviewed at the sickle cell disease clinic. The questionnaire which was used consisted of both open and closed ended questions. The interviews were conducted after the clinic reviews.

3.8 PILOT STUDY

A pilot study is "a small scale study which is conducted before the main study on a limited number of subjects from the same population as that intended for the eventual project", (Blink, H. I., 1996).

The purpose of the pilot study is to investigate the feasibility of the proposed study and to detect possible flaws in the data collecting tool, such as ambiguous questions and to see whether the variables are observable and measurable. The pilot study was done in the hemato-oncology ward on 5 respondents.

3.9 ETHICAL AND CULTURAL CONSIDERATIONS

Ethics can be defined as, "a system of moral values that is concerned with the degree to which research procedures adhere to professional, legal and social obligations to the study participants", Polit, D. F. and Hungler, B. P., (1997).

Before undertaking the study, permission was obtained from the Executive Director at UTH, the Nursing Services Manager, the Head of Paediatrics and Child Health, the Nursing Officer for Paediatrics and the Sister in Charge for Haemato-oncology ward and the sickle cell disease clinic.

A brief explanation of the nature and purpose of the study was given to the respondents in order to obtain informed consent. Those who did not give consent were not included in the study. Anonymity of respondents was ensured by not using names on the answer sheets. Respondents were also assured that the information obtained from them was not be used against them in any way and that it was going be kept confidentially. The respondents were also in a natural setting, that is the clinic they normally use for reviews. Because they were in a natural setting, they were not exposed to any physical or emotional danger or harm.

CHAPTER FOUR

4.0 DATA ANALYSIS AND PRESENTATION OF FINDINGS

4.1 DATA ANALYSIS

The findings from this study are presented according to the sequence of the questions and sections in the questionnaire. Many of them are grouped together to give an overall picture.

The findings have been presented in tables and pie charts. This has been done to assist in examining the relationships among the data collected. Data has been analyzed manually.

SECTION A

The table in section A represents the demographic data of the sample.

SECTION B

The tables in Section B represent the respondent's knowledge about sickle cell disease.

SECTION C

The tables and pie charts in this section represent data about the coping mechanisms of the parents and the problems they face.

4.2 PRESENTATION OF FINDINGS

TABLE 1: DEMOGRAPHIC DATA OF THE SAMPLE

	FREQUENCY	**PERCENTAGE**
Sex		
Male	4	8
Female	46	92
Total	**50**	**100**
Age		
>20	0	0
20-29	25	50
30-39	19	38
40-49	6	12
Total	50	100
Marital Status		
Single	1	2
Married	43	86
Divorced	1	2
On separation	2	4
Widowed	3	6
Total	50	100
Occupational Status		
Housework	25	50
Self employed	10	20
Business	8	16
Formal employed	7	14
Total	50	100
Number of Children		
1	5	10
2	13	26
3	16	32
4	9	18
more than 4	7	14
Total	50	100

The majority of the parents 46 (92%) were female with 4 (8%) males.

25 (50%) of the respondents were in the age group 20-29 years and 19 (38%) in the age group 30-39 years.

43 (86%) respondents were married. 27 (54%) attained secondary education with only 1 (2%) who attained college education. The majority 25 (50%) of the parents are housewives with only 7 (14%) in formal employment.

The size of the family ranged from one child to four children and those with more than four, with the majority of the parents 16 (32%) having three children.

SECTION B

TABLE 2: RESPONDENT'S KNOWLEDGE ABOUT SICKLE CELL DISEASE

	FREQUENCY	PERCENTAGE
Number of sicklers in the family		
1	46	92
2	2	4
3	2	4
Total	50	100
Source of diagnosis of the disease		
Doctor	50	100
Total	50	100
Definition of sickle cell disease		
An inherited blood disease	20	40
An inherited disease that results in shortage of blood in the body	23	46
Disease that can not be treated or controlled leading to death	1	2
Not told	6	12
Total	50	100

The majority of the parents 46 (92%) have one child with sickle cell disease in their families, 2 (4%) have two and the other 2 (4%) have three children with sickle cell disease in their families.

All the parents 50 (100%) stated that their children were diagnosed by a Medical Doctor.

The majority 23 (46%) gave a correct and complete definition of sickle cell disease, followed by 20 (40%) who gave a correct but complete definition of sickle cell disease.

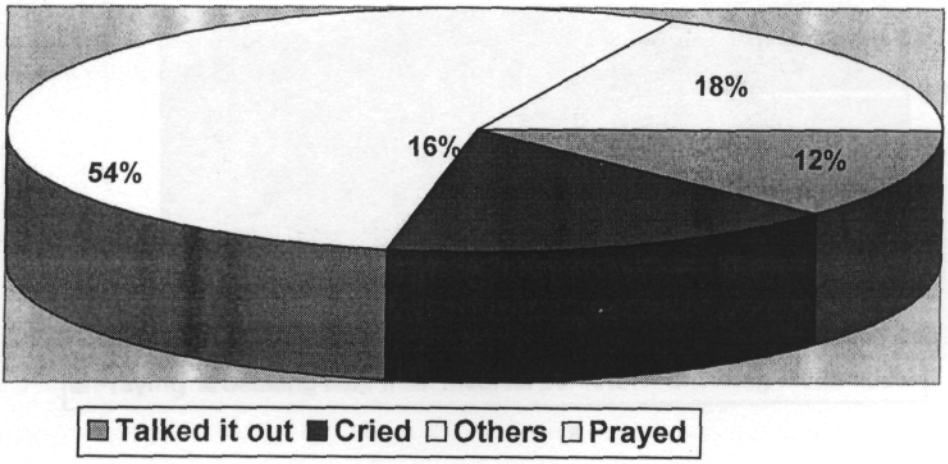
TABLE 3:

THE LEVEL OF KNOWLEDGE OF THE PARENTS ON SICKLE CELL DISEASE

LEVEL OF KNOWLEDGE	FREQUENCE	PERCENTAGE
Low	0	0
Medium	30	60
High	20	40
Total	**50**	**100**

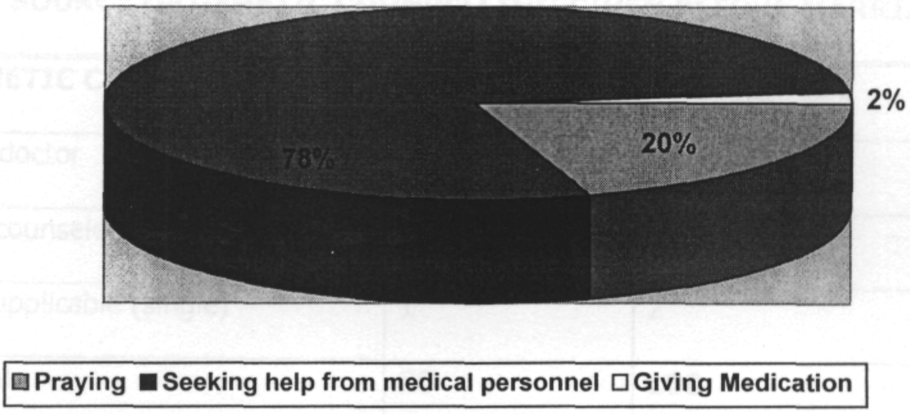
The majority of the parents 30 (60%) have medium knowledge while the other 20 (40%) have high knowledge.

FIGURE 1: THE PARENT'S INITIAL REACTION TO THE DIAGNOSIS



The majority of the parents 27 (54%) had a mixture of reactions, such as acceptance, blaming God, worrying and feeling very bad, about the diagnosis. 9(18%) prayed, 8(16%) cried while 6(12%) talked it out with some body.

FIGURE 2: THE PARENTS' REACTION TO STRESS CAUSED BY THEIR CHILDREN'S CONDITION (COPING MECHANISM)



This shows that, the majority of the parents (39) 78% reacted to stress by seeking help from medical personnel followed by 10, (20%) who reacted to stress by praying.

TABLE 4: GENETIC COUNSELLING BEFORE MARRIAGE

GENETIC COUNSELLING	FREQUENCY	PERCENTAGE
Not counseled	48	96
Counseled	1	2
Not applicable (single)	1	2
Total	**50**	**100**

The majority of the parents 48 (96%) had no genetic counselling only 1 (2%) was counseled.

TABLE 5

THE SOURCE OF GENETIC COUNSELLING GIVEN BEFORE MARRIAGE

GENETIC COUNSELLING	FREQUENCY	PERCENTAGE
The doctor	1	2
Not counseled	48	96
Not applicable (single)	1	2
Total	**50**	**100**

The majority of parents (48), 96% had no genetic counselling before marriage. There was only 1 (2%) who was counselled by the doctor.

TABLE 6

PARENTS WHO WOULD HAVE MARRIED THEIR PARTNERS WHILE FULLY AWARE OF THE COMPLICATIONS OF SICKLE CELL

MARRIAGE AFTER COUNSELLING	FREQUENCY	PERCENTAGE
Yes	21	42
No	27	54
Not applicable	2	4
Total	**50**	**100**

The table shows that, majority of the parents 27 (54%) would not have married their partners if they knew the complications of the disease while 21 (42%) indicated that they would have married their partners.

TABLE 7

EFFECT OF THE DISEASE ON THE COUPLES

EFFECT OF THE DISEASE ON THE COUPLES	**FREQUENCY**	**PERCENTAGE**
Yes	6	12
No	40	80
Not applicable (single or widowed)	4	8
Total	**50**	**100**

The table shows that, the disease had no effect on the majority of the parents 40 (80%) while 6 (12%) were affected by the disease.

TABLE 8

THE TYPE OF EFFECT CAUSED BY THE DISEASE ON THE COUPLES

TYPE OF EFFECT THE DISEASE CAUSED ON THE COUPLES	**FREQUENCY**	**PERCENTAGE**
Confusion in the family as to the cause of the disease	3	6
Separation of the partners	1	2
Blame on the maternal family as the cause of the disease	1	2
Blame that the disease is caused by the mother's promiscuity	1	2
Total	**6**	**12**

This shows that, out of the 6 (12%) affected, the majority 3 (6%) were confused as to what could be the cause of the disease.

TABLE 9

THE RESPONDENTS' PLAN TO HAVE MORE CHILDREN

PLAN FOR MORE CHILDREN	FREQUENCY	PERCENTAGE
Yes	16	32
No	30	60
Not applicable (single or widowed)	4	8
Total	**50**	**100**

The majority of the parents 30 (60%) did not want to have more children while 16 (32%) stated that they wanted to have more children.

TABLE 10

SOCIAL SUPPORT SYSTEM

RECEIVING SOCIAL SUPPORT	FREQUENCY	PERCENTAGE
Yes	46	92
No	4	8
Total	**50**	**100**

The majority of the respondents 46 (92%) receive social support towards the care of the children while 4 (8%) do not receive any social support.

TABLE 11

THE SOURCE OF SOCIAL SUPPORT RECEIVED BY PARENTS

SOURCE OF SOCIAL SUPPORT RECEIVED BY PARENTS	**FREQUENCY**	**PERCENTAGE**
The extended family	23	46
The church	2	4
Both the extended family and the church	21	42
Not applicable	4	8
Total	**50**	**100**

The majority of the parents 23 (46%) receive social support from the extended family followed by 21 (42%) who receives social support from both the extended family and the church.

TABLE 12

THE NUMBER OF TIMES THE CHILD WAS ADMITTED TO HOSPITAL IN THE LAST 12 MONTHS

NUMBER OF ADMISSIONS	FREQUENCY	PERCENTAGE
No admissions	15	30
1 admission	24	48
2 admissions	9	18
3 or more admissions	2	4
Total	**50**	**100**

The majority of the parents 24 (48%) indicated that their children were admitted only once in the past 12 months followed by 15 (30%) whose children had no admissions.

TABLE 13

INFORMATION RECEIVED BY THE PARENTS ON THE CARE OF THEIR CHILDREN AT HOME

INFORMATION ON CARE	FREQUENCY	PERCENTAGE
Received (yes)	43	86
Not received (no)	7	14
Total	**50**	**100**

The majority of the parents 43 (86%) received information on the care of their children at home while 7 (14%) did not.

TABLE 14

THE SOURCE OF INFORMATION ON THE CARE OF CHILDREN AT HOME

SOURCE OF INFORMATION ON CARE OF CHILDREN AT HOME	FREQUENCY	PERCENTAGE
The doctor	10	20
The nurse	26	51
Friend	0	0
Relative	1	2
The doctor and the nurse	6	12
Not applicable	7	14
Total	**50**	**100**

The majority of the parents 26 (52%) received information on the care of their children at home from the nurses while 7 (14%) never received any information.

TABLE 15: ADEQUACY OF INFORMATION

ADEQUACY OF INFORMATION	FREQUENCY	PERCENTAGE
Adequate (yes)	42	84
Not adequate (no)	1	2
Not applicable	7	14
Total	**50**	**100**

The majority of the parents 42 (84%) indicated that the information received was adequate.

TABLE 16

THE PROBLEM PARENTS FACE IN ACCESSING HEALTH SERVICES FOR THEIR CHILDREN

PROBLEMS FACED BY PARENTS IN ACCESSING HEALTH SERVICES FOR THEIR CHILDREN	FREQUENCY	PERCENTAGE
Yes	14	28
No	36	72
Total	**50**	**100**

The majority of the parents 37 (74%) do not experience any problems in accessing health services while 13 (26%) do.

TABLE 17: TYPE OF PROBLEM EXPERIENCED BY PARENTS IN ACCESSING HEALTH SERVICES

TYPE OF PROBLEM EXPERIENCED	FREQUENCY	PERCENTAGE
Long waiting hours in Out Patient Department	2	4
Inadequate income for transport, food and medicine	6	12
Very small ward with poor ventilation and poor sanitation	2	4
Poor staffing and poor staff attitude	3	6

The table shows that out of the 13 (26%) who experiences problems in accessing health services, the majority 6 (12%) indicated that their income was inadequate to cover transport costs, buy medicines and food.

TABLE 18

ADEQUACY OF INCOME TO TAKE CARE OF THE SICKLERS BOTH AT HOME AND DURING HOSPITALIZATION

ADEQUACY OF INCOME	FREQUENCY	PERCENTAGE
Adequate (yes)	25	50
Not adequate (no)	25	50
Total	**50**	**1000**

The table shows that half 25 (50%) of the parents indicated that their income was adequate while the other half 25 (50%) stated that their income was not adequate.

TABLE 19

THE PARENT'S COPING LEVELS TOWARDS THEIR CHILDREN WITH SICKLE CELL DISEASE

LEVEL OF COPING	FREQUENCY	PERCENTAGE
Poorly	0	0
Well	20	40
Very well	30	60
Total	50	100

The majority of the parents 30 (60%) were coping very well with their children while 20 (40%) were coping well.

TABLE 20

PARENTS' SEX IN RELATION TO THE LEVEL OF COPING WITH SICKLE CELL DISEASE

SEX	LEVEL OF COPING			TOTAL
	Poorly	Well	Very well	
Male	-	-	4 (8%)	4 (8%)
Female	-	20 (40%)	26 (52%)	46 (92%)
Total	**-**	**20 (40%)**	**30 (60%)**	**50 (100%)**

The majority of the parents 46 (92%) were females, out of which 26 (52%) were coping very well while 20 (40%) were coping well.

TABLE 21

PARENTS' AGE IN RELATION TO THE LEVEL OF KNOWLEDGE

AGE	LEVEL OF KNOWLEDGE			TOTAL
	Low	Medium	High	
Less than 20 years	-	-	-	-
20-29 years	-	17 (34%)	8 (16%)	25 (50%)
30-39 years	-	10 (20%)	9 (18%)	19 (38%)
40-49 years	-	3 (6%)	3 (6%)	6 (12%)
Total	**-**	**30 (60%)**	**20 (40%)**	**50 (100%)**

The table shows that out of the 20 (40%) of the respondents who had high level of knowledge the majority 9 (18%) were in the age group 30-39 years.

TABLE 22

PARENTS' AGE IN RELATION TO THE LEVEL OF COPING WITH SICKLE CELL DISEASE

AGE	LEVEL OF COPING			TOTAL
	Poorly	Well	Very well	
Less than 20 years	-	-	-	-
20-29 years	-	11 (22%)	14 (28%)	25 (50%)
30-39 years	-	5 (10%)	14 (28%)	19 (38%)
40-49 years	-	4 (8%)	2 (4%)	6 (12%)
Total	**-**	**20 (40%)**	**30 (60%)**	**50 (100%)**

The majority of the parents 14 (28%) who were coping very well were in the age group 20-29 years and 30-39 years, respectively.

TABLE 23

PARENTS' LEVELS OF EDUCATION IN RELATION TO THEIR KNOWLEDGE ON SICKLE CELL DISEASE

LEVEL OF EDUCATION	**LEVEL OF KNOWLEDGE ON SICKLE CELL DISEASE**			**TOTAL**
	Low	Medium	High	
None	-	-	1 (2%)	1 (2%)
Primary	-	13 (26%)	8 (16%)	21 (42%)
Secondary	-	17 (34%)	10 (20%)	27 (54%)
College	-	-	1 (2%)	1 (2%)
Total	**-**	**30 (60%)**	**20 (40%)**	**50 (100%)**

The table shows that, out of the 20 (40%) who had high knowledge on sickle cell disease, the majority 10 (20%) had secondary education.

TABLE 24

PARENTS' LEVEL OF EDUCATION IN RELATION TO THE LEVEL OF COPING WITH SICKEL CELL DISEASE

LEVEL OF EDUCATION	**LEVEL OF COPING**			**TOTAL**
	Poorly	Well	Very well	
None	-	1 (2%)	-	1 (2%)
Primary	-	8 (16%)	13 (26%)	21 (42%)
Secondary	-	11 (22%)	16 (32%)	27 (54%)
College	-	-	1 (2%)	1 (2%)
Total	**-**	**20 (40%)**	**30 (60%)**	**50 (100%)**

The table shows that, out of the 30(60%) who were coping very well more than half 16(32%) had secondary school education.

TABLE 25

THE NUMBER OF SICKLERS IN THE FAMILY IN RELATION TO THE PARENTS' ABILITY TO COPE

NUMBER OF SICKLERS IN THE FAMILY	**LEVEL OF COPING**			**TOTAL**
	Poorly	Well	Very well	
1	-	18 (36%)	28 (56%)	46 (92%)
2	-	-	2 (4%)	2 (4%)
3	-	2 (4%)	-	2 (4%)
4	-	-	-	-
Total	**-**	**20 (40%)**	**30 (60%)**	**50 (100%**

The table shows that out of the 30(60%) who were coping very well, the majority 28(56%) had only one child with sickle cell disease in their families.

TABLE 26

PARENTS' LEVEL OF KNOWLEDGE ON SICKLE CELL DISEASE IN RELATION TO THEIR LEVEL OF COPING

LEVEL OF KNOWLEDGE ON SICKLE CELL DISEASE	**LEVEL OF COPING**			**TOTAL**
	Poorly	Well	Very well	
Low	-	-	-	-
Medium	-	11 (22%)	19 (38%)	30 (60%)
High	-	9 (18%)	11 (22%)	20 (40%)
Total	**-**	**20 (40%)**	**30 (60%)**	**50 (100%)**

The table shows that out of the 20 (40%) of parents who had high knowledge 11 (22%) were coping very well while 9 (18%) were coping well.

TABLE 27

SOCIAL SUPPORT IN RELATION TO THE ABILITY OF THE PARENTS TO COPE

SOCIAL SUPPORT	**LEVEL OF COPING**			**TOTAL**
	Poorly	Well	Very well	
Yes	-	18 (36%)	28 (56%)	46 (92%)
No	-	2 (4%)	2 (4%)	4 (8%)
Total	**-**	**20 (40%)**	**30 (60%)**	**50 (100%)**

The majority of the parents 28 (56%) who were coping very well were receiving social support.

TABLE 28

INFORMATION ON THE CARE OF CHILDREN AT HOME IN RELATION TO THE LEVEL OF COPING

INFORMATION ON CARE	**LEVEL OF COPING**			**TOTAL**
	Poorly	Well	Very well	
Yes	-	13 (26%)	30 (60%)	43 (86%)
No	-	7 (14%)	-	7 (14%)
Total	**-**	**20 (40%)**	**30 (60%)**	**50 (100%)**

The table shows that out of out of 43 (86%) who received information on the care of their children at home, more than half 30 (60%) were coping very well.

TABLE 29

ACCESS TO HEALTH SERVICES IN RELATION TO THE LEVEL OF COPING

ACCESS TO HEALTH SERVICES	LEVEL OF COPING			TOTAL
	Poorly	Well	Very well	
Yes	-	12 (24%)	2 (4%)	14 (28%)
No	-	8 (16%)	28 (56%)	36 (72%)
Total	**-**	**20 (40%)**	**30 (60%)**	**50 (100%)**

The table shows that out of 36 (72%) who had no problems in accessing health services, more than half 28 (56%) were coping very well.

TABLE 30

ADEQUACY OF INCOME IN RELATION TO THE NUMBER OF ADMISSIONS

ADEQUACY OF INCOME	**NUMBER OF ADMISSIONS**				**TOTAL**
	0	1	2	3	
Yes	10 (20%)	12 (24%)	1 (2%)	2 (4%)	25 (50%)
No	5 (10%)	12 (24%)	8 (16%)	-	25 (50%)
Total	**15 (30%)**	**24 (48%)**	**9 (18%)**	**2 (4%)**	**50 (100%)**

The table shows that out of 25 (50%) who had adequate income 12 (24%) had only one admission followed by 10 (20%) who had no admission at all in the past 12 months.

CHAPTER FIVE

5.0 DISCUSSION OF FINDINGS AND IMPLICATIONS FOR THE HEALTH CARE SYSTEM

5.1 CHARACTERISTICS OF THE SAMPLE.

The sample consisted of 50 parents who brought their children with sickle cell disease for review at the sickle cell disease clinic of the University Teaching Hospital.(Lusaka).(46) 92% were females and (4)8% were males, (Table1).

The parents` ages ranged between 20 to 49 years, with the majority (25) 50% aged between 20 to 29 years followed by (19) 38% who were aged between 30 to39 years. This age range is a true reflection of the scenario in Zambia, where most Zambian women who are bearing and raising children are aged between 20 to 29 years. Matabile, J. {2002}.

The marital status was mainly married (43)86%, widowed (3)6%, on separation (2)4%, (1)2% single and the other (1)2% divorced. This is a true reflection of marriage being an important socio-cultural activity in Zambia where most individuals would like to get married at a certain age.

The respondents` educational background ranged from secondary school (27)54%, primary school (21)42%, college (1)2% and (1)2%who never went to school (Table 1).This is contrary to the results of a study by Matabile, J, (2002) on the knowledge ,attitude and practice of the patients` care givers at the University Teaching Hospital which revealed that more than half (61%) of the respondents have only been to primary school.

The parents` occupational status were: house wives(25)50%; self employed (10)20%; Business activities (8)16% and formally employed (7)14% (Table 1).This meant that the majority of the respondents had no source of income.

This result ties with the results of a study by Kanfwa,E.,(1998)on the effect of sickle cell disease on the life of the sickler at the University Teaching Hospital, which revealed that, many mothers of children with sickle cell disease give up on their employment to look after their children as they have to be on the child` bed side.

The number of children in the respondents` families ranged from 1 to 4 and those with more than 4. The majority (16)32% had 3 children, (13)26% had 2 children, (9)18% had 4 children, (7) 14% had more than 4 children while (5)10% had one child (Table 1).
From this study, it clearly indicates that the average family size for parents who have children with sickle cell disease is 3. Most of the parents (30) 60% did not express any desire to have more children after realizing that they were carriers of the sickle cell trait (Table 9).

5.2 DISCUSSION OF VARRIABLES-

5.2.1 KNOWLEDGE

In order to cope well with a condition, an individual needs to understand what it is, how it s transmitted, how it is treated, and know certain measures that can be undertaken to minimize it`s impact .Knowledge about sickle cell disease was elicited from the parents through questions in section B of the questionnaire (appendix 1).

The findings of this study shows that, the majority of the respondents (30) 60% have medium level of knowledge about sickle cell disease while the other (20) 30% have high knowledge levels (Table 3).This tallies with the level of education of the respondents where although the majority (27)54% attained secondary education, they only went up to grade 9 which explains why the majority have medium level of knowledge.

The majority of the respondents (23) 46% gave a correct and complete definition of sickle cell disease, followed by (20) 40% who gave a correct but incomplete definition,(1) 2% gave a wrong definition while (6) 12% indicated that they were not told as a result they did not know what sickle cell disease was (Table 2). This indicates the majority of the parents were taught in the clinic what sickle cell disease is.

From the responses given to the question on the number of children with sickle cell disease they had in their families, it was found out that the majority (46) 92% had one child with sickle cell disease, (2) 4% had 2 and the other (2) 4% had 3 children with sickle cell disease (Table2). When asked about the source of diagnosis for their children`s condition, all the respondents (50) 100% indicated that the diagnoses were made by medical doctors after sickling tests were carried out.

This study has also revealed that all the respondents (50) 100% had no other beliefs as to what sickle cell disease was apart from what they were told by the medical personnel. This implies that the parents understood that sickle cell disease was a genetic condition as opposed to being caused by witchcraft or other myths.

5.2.2 COPING MECHANISMS

Section C of the questionnaire (Appendix 1) contained questions that aided in determining the coping mechanisms and problems faced by parent who have children with sickle cell disease. According to Kozier,B., et al (2000),there are two main coping mechanisms employed by people undergoing stressful situations . These are, short term and long term coping mechanisms.

This study has revealed that the parents` initial reaction to the diagnosis of sickle cell disease varies. The majority (27) 54% had a mixture of reactions, such as acceptance, blaming God, worrying about the prognosis of their child`s condition and feeling that they are the cause of the disease.(9) 18% prayed to God, for God to either heal their child or to give them strength to endure through the crisis.(8) 16% cried while (6) 12% talked it out with some body to seek comfort (Figure 1). The initial reactions are the short term coping mechanisms .This implies that people reacts very differently to crisis, they may not have one set of reaction but a mixture, thus medical personnel should take this into account when caring for people undergoing a crisis.

The parents` reaction to stress caused by their children`s condition is shown in figure2;(Long term coping mechanisms).The majority (39)78% coped by seeking for help from medical personnel when ever their child had a crisis or when experiencing any problem related to their child`s condition. (10) 20% prayed to God when ever they were stressed up while only (1) 2% gave medication to the child. This is an indication that the parents have complied with medical advice and regimen as indicated by the majority of them seeking help from medical personnel when ever their child had a crisis.

This study further revealed that, the majority of the parents (48) 96% had no genetic counseling before marriage, (1)2% was single while only (1)2% was counselled (Table 4).The only one who was counseled, the counseling was done by the doctor (Table 5). It appears that there is no genetic counselling in Zambia per-se given to couples before marriage except to those who already have children with sickle cell disease. It implies that even the pre-marital counselling given at churches focuses only on biblical issues and now HIV/AIDS and not on genetics.

This result tallies with the results that emanated from a study by Sakwimba, L.C.K.,(1987)on the coping mechanisms of parents with children who have sickle cell disease where all the married respondents (41) 84% had no genetic counselling before marriage.

Out of the 96% who had no genetic counselling the majority (27) 54% indicated that they would not have married their partners if they were counselled and aware of the complications of sickle cell disease

(Table 6).This shows that if couples have genetic counseling before marriage then cases of sickle cell disease will be reduced as many couples would not go ahead to get married with full awareness of the complication of sickle cell disease. Although this may be difficult to ascertain knowing how unpredictable human behavior is especially under the emotional influence of love.

In Table 7,the study has revealed that the majority of the respondents (40) 80% stated that the disease had no effect on their marriage. It was realized from the study that, the genetic counselling given after the diagnosis enabled the couples to understand that both husband and wife equally contributed towards the child `s illness, thus there was no need to blame each other. However (6) 12% of the respondents` marriages were affected by the disease despite the counselling. Out of the (6) 12% who were affected, the effect ranged from confusion as to the cause of the disease, separation of the couple, blame on the maternal family as being the cause of the disease and blame on the mother that the disease was caused by her promiscuity (Table 8).

In assessing how serious sickle cell disease is, no one should underestimate the emotional and social impact of the disease. For the family there is nothing more heart breaking than to watch their child endure extreme pain and life threatening medical conditions. The patient endures not only the pain itself but also the emotional strain from unpredictable bouts of pain, fear of death and social isolation, http:// wellness. ucadavis-edu/ medical conditions az / sickle cell 58.html.

The results of this study has revealed that the majority of the respondents (46) 92% received social support while (4) 8% did not (Table 10).Out of the 92% who received social support,(23) 46% the support was from the extended family,(2) 4%,the support was from the church while (21)42% the support was from both the church and the extended family (Table 11).This implies that the extended family system is still strong in Zambia making social support possible.

This study has further revealed that, out of the 92% who received social support towards the care of their children, more than half (28) 56% were coping very well with the condition (Table27).This has emphasized the need for social support in enabling individuals undergoing stressful conditions to cope. It has also proven hypothesis number 1.6.2 which says, "the higher the social support given to the parents by the extended family, the church and the community the better the coping".

The number of times children were admitted to the hospital in the past 12 months are shown in (Table 12).The majority of the parents (24)48% indicated that their children were admitted only once in the past 12 months followed by (15)30% whose children had no admissions,(9)18% indicated that their children had two admissions while (2) 4% indicated that their children had three or more admissions. These findings tally with the results of a study by Sakwimba, L, (1987)on the coping mechanisms of parents whose children have sickle cell disease which revealed that the majority of the parents (36) 72% had their children admitted only once in 12 months.

Information on the care of children with sickle cell disease is very important so as to prevent exposing the child to extreme conditions which can trigger a crisis. The findings of this study has indicated that the majority of the parents (43) 86% received information on the care of their children at home while only (7)14% did not (Table 13).Out of the (43)86% who received information ,majority (26) 52% got the information from the nurse,(10)20% from the doctor ,(6)12% from both the nurse and the doctor while only (1) 2% got the information from a relative (Table 14).This implies that the doctors and nurses were playing their part in giving health education to the parents as only the newly diagnosed had not yet received information on the care of their children at home.

Out of the 86% who received information, the majority (42) 84% said the information was adequate in assisting the parents to care for their children at home while only (1) 2% said the information was not adequate (Table 15). This is an indication that the information received from the health personnel was useful.

The study has also revealed that, out of the (43) 86% who received information on the care of their children at home, more than half (30)60% were coping very well (Table 28).This means that if parents are given information on how to care for their children at home they will be in a position to care for their children, minimize admissions and cope with the disease.

Access to health services has a great influence on the health of individual especially those with chronic illnesses. (36) 72% of the respondents indicated that they had no problems in accessing health services while (14) 28% indicated that they experienced problems in accessing health services (Table 16).

Out of (14) 28% of the respondents who experienced problems in accessing health services, they cited the following problems:

a) Long waiting hours in the Out Patient Department;
b) Inadequate income for transport costs, food and medication;
c) Very small ward with poor ventilation and sanitation; and
d) Poor staffing and Poor staff attitude.

This confirmed the results of a study by Matabile. J (2002) as already cited, who said that; " slightly more than half of the respondents were unhappy with the living conditions on the ward (haemato-oncology ward). They said the ward needs a lot of improvements in the areas of the toilets, bathrooms, ventilations, food and beddings.

It was also discovered from the study that, out of the (36) 72% of the respondents who had no problems in accessing health services, more than half (28) 56% were able to cope very well with their children with sickle cell disease. On the other hand, out of the (14) 28% who had problems in accessing health services, the majority (12) 24% were not able to cope very well with the condition of their Children. This means the hypothesis number 1.6.3, which says, " Poor access to health facilities due to long distance, user fees and long waiting hours leads to poor ability to cope with the conditions " was accepted.

The study by Kanfwa E. (1998) on the "effects of sickle cell disease on the life of the sickler at the University Teaching Hospital" states that " socio-economic status appear to be directly related to the number of admissions, while the nutrition status, the environment and prompt medical care have a large role to play in the life of the sickler." In support of this finding the results of this study in (Table 18) shows that half of the respondents (25) 50% had an adequate income while the other half (25) 50% did not have an adequate income. Out of (25) 50% who had an adequate income (12) 24% had only one admission in twelve (12) months followed by (10) 20% who had no admission at all in twelve (12) months (Table 30)

This means that with an adequate income the family is able to feed the child well, clothe the child adequately and have a consistent supply of iron and anti-malarial tablets. This in turn reduces on the number of crises thereby reducing on the number of admissions.

The study findings have revealed that the majority of the respondents (30) 60% were coping very well while the other (20) 40% were coping just well (Table 19).

Out of the (30) 60% who were coping very well, the majority

(14) 28% were in the age groups 20 to 29 years, and 30 to 39 years respectively (Table 22).This implies that those in the middle age are better able to cope with stress as compared to their younger and elderly counter parts. The explanation for this could be that those in the middle age are physically able economically sounds to cope better.

The level of education in relation to the level of coping is shown in (Table 24). This table has shown that, out of the (30)60% who were coping very well more than half (16) 32% had secondary education. This finding has proven hypothesis number 1.6.1which states that "parents with high level of education cope better with sickle cell disease than those with low level of education" has been accepted.

According to Kozier. B. Et al (2000) "there are several factors which influence the effectiveness of coping by individuals among them being the number, duration and intensity of the stressor. In support of this sentiment, this study has revealed that, out of (46) 92% who had one child with sickle cell disease, more than half (28) 52% were able to cope very well, on the other hand none of those who had 3 children with sickle cell disease were able to cope very well (Table 25).

This means that if the number of stressors is reduced then an individual is better able to cope as compared to one with several stressors.

This study has further revealed that knowledge about a condition is very important in enabling an individual to adjust and cope. Analysis of the data has shown in (Table 26) that, out of the (20) 40% who had high knowledge about sickle cell disease, more than half (11) 22% were coping very well.

5.3 IMPLICATION TO THE HEALTH CARE PROVIDERS.

The study findings have shown that knowledge on sickle cell disease is very important in assisting parents to cope with the condition . It has been realized from the study that, those parents who have information on the care of their children at home and those who have high knowledge levels on sickle cell disease were coping very well. This implies that to keep the parents informed and knowledgeable about the disease, a teaching plan should be formulated to cover all aspects of the disease.

Health care providers such as nurses and doctors who are taking care of children with sickle cell disease should counsel the parents to enable them understand and accept the condition.

All those caring for children with sickle cell disease should advocate for a formation of a support group for the patients and their families. This will enable these patients and their families to get social support and meet with others who have the same condition.

5.4 CONLUSSION

The study sought to determine the coping mechanisms of parents who have children with sickle cell disease. The objectives of the study have been achieved and the three hypotheses have been accepted.

It was established that there are many factors which influence the parents' ability to cope with sickle cell disease, these include: the level of education; their level of knowledge on sickle cell disease; the number of children with sickle cell disease they have; the social support they receive;

their income; and their access to health facilities. It has been realized that those parents who were on the high or positive side of the above attributes were coping better than those on the opposite side.

5.5 RECOMMENDATIONS

1. The University Teaching Hospital being the largest referral hospital for children with sickle cell disease in the country, it's management and staff should come up with a formal teaching plan for the parents to enable them to understand the disease and be able to look after their children adequately at home.

2. The health care providers should advocate for the formation of a social support group for patients and their families.

3. The hospital authority should have a provision to exempt children with sickle cell disease from cost sharing since this is a chronic illness. This will ease the patients' accessibility to health services.

5.6 DISSEMINATION OF FINDINGS

The results of this study will be disseminated by sending an executive summary to the research site which is the University Teaching Hospital for implementation of the finding

There will also be a symposium organized for all the members of staff in the haemato-oncology department and any other interested parties in sickle cell disease where the findings of the study will be disseminated.

5.7 LIMITATIONS OF THE STUDY

The sample size used {50} was too small and therefore not representative of the population. This was due to limited resources in terms of finances and time.

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APPENDIX 1

THE UNIVERSITY OF ZAMBIA
SCHOOL OF MEDICINE

DEPARTMENT OF POST BASIC NURSING

STRUCTURED INTERVIEW SCHEDULE

TOPIC: A STUDY TO DETERMINE THE COPING MECHANISMS OF PARENTS WHO HAVE CHILDREN WITH SICKLE CELL DISEASE

DATE OF INTERVIEW……………………………………………………………………
PLACE OF INTERVIEW…………………………………………………………………
NAME OF INTERVIEWER………………………………………………………………
SERIAL NUMBER…………………………………………………………………………

INSTRUCTIONS

1. Introduce yourself to the respondent.
2. Explain the purpose of the interview
3. Assure respondents of confidentiality and anonymity
4. Get verbal consent from the respondent before the interview
5. Tick (✓) in the box corresponding to the correct answer or state response (s) in the space provided.
6. Do not write the name of the respondent.

SECTION A: DEMOGRAPHIC DATA

For official use only

1. Sex:

(a) Male ☐ (b) Female ☐

☐

2. What was your age on your last birthday?...............

3. What is your marital status?
   - (a) Single ☐
   - (b) Married ☐
   - (c) Divorced ☐
   - (d) Separated ☐
   - (e) Widowed ☐

☐

4. What is your religion?
   - (a) Christian ☐
   - (b) Moslem ☐
   - (c) Hindu ☐
   - (d) Buddhist ☐
   - (e) Others (specify)..................................

☐

5. What is the highest level of education you have attained?
   - (a) None ☐
   - (b) Primary ☐
   - (c) Secondary ☐
   - (d) College ☐
   - (e) University ☐

☐

6. What do you do for a living?
   - (a) House work ☐
   - (b) Business ☐
   - (c) Self employed ☐
   - (d) Formal employed ☐
   - (e) Unemployed ☐

☐

7. How many children do you have?

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- (a) One ☐
- (b) Two ☐
- (c) Three ☐
- (d) Four ☐
- (e) More than 4 ☐

SECTION B: KNOWLEDGE

8. How many of your children have sickle cell disease?.........

9. Who told you that your child/children have sickle cell disease? ☐

- (a) The Doctor ☐
- (b) The Nurse ☐
- (c) Others, (specify)...

10. What is sickle cell disease from what you were told?

____

____

11. Do you have any other belief as to what sickle cell disease is? ☐

- (b) Yes ☐
- (c) No ☐

12. If "Yes" to question 11, specify.______________________

____

SECTION B: COPING

13. How did you react when you were told that your child has sickle cell? ☐

- (a) Cried ☐
- (b) Prayed ☐
- (c) Consulted a witchdoctor ☐
- (d) Talked it out with somebody ☐
- (e) Others, specify...

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14. Which of the following behaviour do you use to deal with stress caused by your child's condition? ☐

- (a) Crying ☐
- (b) Praying ☐
- (c) Consulting a witchdoctor ☐
- (d) Seeking help from medical personnel ☐
- (e) Others, (specify)..

15. Did you receive any genetic counseling before you got married? ☐

- (a) Yes ☐
- (b) No ☐

16. If "Yes", to question 15, who counseled you? ☐

- (a) The Doctor ☐
- (b) The Nurse ☐
- (c) Others, (specify)..

17. If "No" to question 15, would you have married your partner if you knew about the complications of sickle cell disease? ☐

- (a) Yes ☐
- (b) No ☐

18. Has the sickle cell disease of your child affected the Relationship between you and your partner? ☐

- (a) Yes ☐
- (b) No ☐

19. If "Yes" to question 18, how has it affected your relationship Between you and your partner?

____

____

____

20. Are you planning to have more children with your partner? | official use only

(a) Yes ☐
(b) No ☐

☐

21. Do you receive any support towards the care of your child?

(a) Yes ☐
(b) No ☐

☐

22. If "Yes", to question 21, who gives you the support? (tick the correct answers)

(a) The extended family ☐
(b) The Church ☐
(c) Others, (specify)________________________

☐

23. How often has your child been admitted in the last 12 months? ____________________

24. Have you ever received any information on the care of your child at home?

(a) Yes ☐
(b) No ☐

☐

25. If "Yes" to question 24, who gave you the information?

(a) The Doctor ☐
(b) The Nurse ☐
(c) Friend ☐
(d) Relative ☐
(e) Others (specify)..

☐

26. If "Yes" to question 24, has the information been Adequate in helping you to manage your child?

(a) Yes ☐
(b) No ☐

☐

27. Do you experience any problem in accessing health services?

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(a) Yes ☐
(b) No ☐

☐

28. If "Yes" to question 26, how?____________________

____

____

29. Is your income adequate to take care of your child at home and during hospitalization?

(a) Yes ☐
(b) No ☐

☐

THANK YOU VERY MUCH FOR YOUR COOPERATION

APPENDIX II: WORK SCHEDULE

NO.	TASK TO BE PERFORMED	DATES	PERSONNEL ASSIGNED TO THOSE TASKS	PERSON DAYS REQUIRED
1.	Literature review	Continuous	Researcher	-
2.	Finalizing the Research Proposal	Week 2-7 June 9th to July 28th	Researcher	1 x49 days = 49
3.	Data Collection Tool	Week 7-8 July 28th to August 11th	Researcher	1 x 14 days – 14 days
4.	Clearance from National and funding authority	Week 10 – 15 August 25th to Sep 15th	PBN Supervisor Ethical Committee and Study Setting	1 x 42 days = 42 days
5.	Conducting Pilot Study	Week 12 August 25th to Sept 1st	Researcher	1 x 7 days = 7 days
6.	Data Collection	Week 14 – 17 Sept. 8th – Oct. 5th	Researcher Research Assistants (x2)	1 x 28 days = 28 days
7.	Data Analysis	Week 18 -24 Oct. 6th – Nov 17th	Researcher	1 x 49 days = 49 days
8.	Report Writing	Week 25 -29 Dec. 15th – Dec. 29th	Researcher	1 x 14 days = 14 days
9.	Finalizing of report	Week 30 – 34 Dec. 30th – Jan. 30th	Researcher	1 x 21 days = 21 days
10.	Monitoring and evaluation	Continuous	Researcher	-

APPENDIX III: GANTT CHART
2003 – 2004

NO	TAKS TO BE PERORMED	RESPONSIBLE PERSON	JUNE	JULY	AUG	SEPT	OCT	NOV	DEC	JAN	FEB
1.	Literature Review	Researcher		←	—	—	—	—	—	—	→
2.	Finalizing the Research Proposal	Researcher	←	→							
3.	Data Collection Tool	Researcher		←	→						
4.	Clearance	Facilitator			←	→					
5.	Pilot Study	Researcher			←	→					
6.	Data Collection	Research Team				←	→				
7.	Data Analysis	Researcher					←	→			
8.	Report Writing	Researcher						←	→		
9.	Draft Report to PBN	Researcher							←	→	
10.	Finalization of Report	Researcher									↔
11.	Monitoring an evaluation	Researcher	←	—	—	—	—	—	—	—	→

APPENDIX IV: BUDGET

BUDGET CATEGORY	**UNIT COST (K)**	**QUANTITY**	**TOTAL**
1. **STATIONERY**			
(a) Bond paper	30,000.00	X 2 reams	60,000.00
(b) Pens	500.00	X 8	4,000.00
(c) Pencils	300.00	X 8	2,400.00
(d) Rubber	2,000.00	X 3	6,000.00
(e) Notebooks	6,000.00	X 3	18,000.00
(f) Tippex	5,000.00	X 2	10,000.00
(g) Scientific calculator	35,000.00	1	35,000.00
(h) Research bags	45,000.00	x 3	135,000.00
(i) Stapler	20,000.00	1	20,000.00
(j) Staples	5,000.00	1 box	5,000.00
(k) Perforator	20,000.00	1	20,000.00
SUBTOTAL			315,000.00
2. PERSONNEL			
(a) Lunch allowance			
Researcher	35,000.00	X 1 x 10 days	350,000.00
Research Assistants	35,000.00	X 2 x 5 days	350,000.00
(b) Transport allowance			
Researcher	5,000.00	X 1 x 10 days	50,000.00
Research Assistants	5,000.00	X 2 x 5 days	50,000.00
SUBTOTAL			**800,000.00**
3. TYPING SERVICES			
(a) Typing and printing interview schedule	3,000.00	X 5 days	15,000.00
(b) Research Proposal typing	3,000.00	X 80 pages	150,000.00
(c) Research Proposal photocopying	200.00	X 50 pages	10,000.00
(d) Photocopying interview schedule	200.00	X 50 copies x 5 pages	50,000.00

(e) Research Report typing	3,000.00	100 pages	300,000.00
(f) Research Report photocopying	200.00	x 100 pages x 4 pcs	
(g) Binding Proposal	10,000.00	1 copy	10,000.00
(h) Binding Report	50,000.00	X 4 copies	200,000.00
(i) Diskettes	5,000.00	X 4	20,000.00
SUBTOTAL			**835,000.00**
CONTINGENCY FUND	**10% OF TOTAL BUDGET**	**10/100 X 1,950,400**	**195,040.00**
GRAND TOTAL			**2,145,040.00**

JUSTIFICATION FOR THE BUDGET

STATIONERY

The two reams of bond paper were used for the research proposal and the final research report as well as extra copies of the report. In addition to this, the questionnaire which consists of 5 pages was photocopied to make 50 copies. The research bags were used to ensure that the research questionnaires were kept safely. The scientific calculator was required for data analysis.

Other accessories were required for routine collection of data eg pens, pencils, notebooks, staples, perforators, etc.

PERSONNEL

Data collection was conducted throughout the day and due to limited time allocated, the investigator needed two research assistants. Therefore the investigator and her research assistants needed lunch and transport allowances.

TYPING SERVICES

The investigator required the questionnaire to be typed. Research proposal and research report were typed and photocopied, hence the figure allocated in the budget. Diskettes were required to copy all the data for safety of the research document.

Finally the contingency fund which is 10% of the total budget was used for any extra costs due to inflation of prices and for any eventualities.

The University of Zambia
School of Medicine
Department of Post Basic Nursing
P. O. Box 50110
LUSAKA

31st July, 2003

The Nursing Services Manager
University Teaching Hospital
P/B RW 1X
LUSAKA

[illegible]
Request Approved

Ufs: The Head
Department of Post Basic Nursing
P. O. Box 50110
LUSAKA

31 JUL 2003
BASIC NURSING

Dear Madam,

RE: PERMISSION TO CARRY OUT A RESEARCH STUDY IN HEMATO-ONCOLOGY WARD (A-BLOCK) AND SICKLE CELL DISEASE CLINIC

I am a fourth year student at the Department of Post Basic Nursing doing a Bachelor of Science degree in Nursing.

In partial fulfillment of the requirement of the programme, I am required to carry out a research project. My topic is **"to determine the coping mechanisms used by parents who have children with sickle cell disease"**.

I hereby request for your permission to administer questionnaires on parents nursing their children in hemato-oncology ward and those bringing their children for review at the sickle cell disease clinic. I intend to collect data in September, 2003.

Yours faithfully,

Katowa Patricia Mukwato (Mrs.)

Please take the permission
from Prof Chintu
Head, Haemato-Oncology Unit

However the Dept. encourage
such studies. I would suggest
that you present your
study

Prof G.J. Bhat
1st. Aug 2003.

c.c The Executive Director
University Teaching Hospital
P/B RW 1X
LUSAKA

The Head
Department of Paediatrics and Child Health
University Teaching Hospital
P/B RW 1X
LUSAKA

The Nursing Officer
Department of Paediatrics (A-Block)
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