PROBLEMS ENCOUNTERED BY IMMEDIATE FAMILIES IN CARING FOR CHILDREN AFFECTED WITH SICKLE CELL DISEASE.

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DECLARATION

I hereby declare that with the exception of the assistance acknowledged and the references indicated, the work presented in this Dissertation for the Masters of Science in Nursing is the result of my own work. This work has not been presented either wholly or in part for any other degree and is not currently submitted for any other degree.

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CERTIFICATE OF APPROVAL

This dissertation of Mercy Mumba WaSomwe has been approved as partial fulfilment of the requirements for the award of Masters of Science in Nursing Degree by the University of Zambia.

SIGNED.....DATE.....13th 2011

Examiner I

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Examiner II

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Examiner III

DEDICATION

To all the children with Sickle Cell Disease.

To my husband Dr Somwe Wa Somwe for all the love and inspiration.

My lovely little son Nathan Wa Somwe whose smiles and laughter keeps me going!!!!!!

GOD BLESS.

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ABSTRACT

Sickle Cell Disease (SCD) is a chronic incurable genetic blood disorder that affects the Haemoglobin (Hb) within the Red Blood Cell (RBC).The disease affects millions of people throughout the world and is one of the most prevalent and costly genetic disorder. It is also found in people of African heritage, Mediterranean, Caribbean, South and Central America, Arabian and Indian ancestry.

Patients with SCD experience and endure frequent and prolonged bouts of pain and suffer from several complications associated with the disease. This requires multiple hospitalizations and causes a misery of burden. The family experiences several problems in caring and managing these children.

The aim of the study was to assess the problems encountered by immediate families in caring for children affected with SCD. The study was a descriptive cross sectional study conducted at University Teaching Hospital (UTH) paediatrics department. The study sample consisted of 145 parents and guardians of children affected with SCD seen at UTH SCD outpatient clinic. The study population was sampled using non probability sampling method known as convenient sampling.

A structured interview schedule consisting of both closed and open ended questions was used to collect both qualitative and quantities data. SPSS version 16 was used to analyze data. Chi square test was used to measure association between variables. The cut off point for statistical significance was 0.05.

The study revealed that majority of respondents (63%) had low levels of knowledge of SCD. There was a strong association between level of education and knowledge of the disease (p value 0.01).The level of knowledge also influenced the frequency of hospital hospitalizations

The study revealed that the majority of respondents experienced financial burdens in caring for children affected with SCD and this was a major source of anxieties to the families. There was an association between monthly income and families borrowing money to take care of family needs (p value 0.01). The studies revealed that, majority of the mothers (69%) of the affected children were unable to work because of the responsibilities of caring for the affected child.

This study revealed that respondents and their family members experienced psychological problems which included depression, anxiety, feelings of guilt and episode of blue moods. There was a significant association between the number of times the child had been hospitalized and depression in the parent (p value 0.01).

The study revealed social problems experienced by the families of affected children ranging from poor interpersonal relationships within the home environment, stigmatization, inadequate social support and poor relationship between spouses. There was an association between joint spousal counselling on SCD and relationship between spouses being affected (p value 0.02).

The investigator recommends that the Ministry of Health should put in place National SCD programmes and introduce effective and efficient IEC programmes to make the communities in our country aware of SCD. There is need to establish SCD clinics in all District hospitals and major rural health centres for effective management of SCD patients. There is need for the formation of a Zambia SCD Association which will bring into focus the public health importance of providing strategies for support to the patients and their immediate families. There is also need for mandatory genetic counselling in order to prevent increased incidence of SCD.

It is envisaged that the study results will be used by service delivery area, Ministry of health and interested parties to help put up measures to alleviate problems experienced by immediate family members so as to help improve the quality of life for affected children and their families.

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ACRONYMS USED

Hb - Haemoglobin

HRQOL - Health Related Quality of Life

HIV - Human immune virus

IEC - Information, Education and communication

RBC - Red Blood Cells

SCD - Sickle Cell Disease

SCDAA - Sickle Cell Disease Association of America

TB - Tuberculosis

UN - United Nations

UNZA - University of Zambia

UTH - University Teaching Hospital

USA - United States of America WHO - World Health Organization

ZMK – Zambian Kwacha

CHAPTER ONE

1.0 INTRODUCTION

1.1 BACKGROUND INFORMATION

Sickle Cell Disease (SCD) affects millions of people throughout the world and is one of the most prevalent and costly genetic disorder (WHO 2006). It is known to be widespread reaching its highest prevalence in people of African heritage. However, it is also found in persons of Mediterranean, Caribbean, South and Central America, Arabian and Indian ancestry (WHO 2006). Children who inherit the gene from both parents will develop SCD while those who inherit the gene from only one parent, will have the sickle cell trait and pass it on to their off springs (www.sicklecelldisease.org/about scd/affected accessed 5 May 2009).

In America, according to the Sickle Cell Disease Association of America, SCD is the most common inherited blood diseases affecting approximately between 72,000-80,000 people most of whose ancestors come from Africa (Royster 2007).The disease occurs approximately 1 in every 500 African- American births, 1 in every 1,000 Hispanic births, 1 in 58,000 Caucasians. This makes SCD the most common long term illness identified in these populations, and results in an estimated 750,000 hospitalization a year. The cost of these hospitalizations is estimated at $ 475 million annually (Royster, 2007).

In African countries such as Cameroon, Republic of Congo, Gabon, Ghana, Nigeria and Zambia, the prevalence is between 20-30 % of the population, while some parts such as Uganda it is as high as 45% (WHO 2006).

SCD is a chronic incurable genetic blood disorder that affects the Haemoglobin (Hb) within the Red Blood Cells (RBC). In SCD, RBC contains an abnormal form of oxygen carrying protein known as Haemoglobin S (Hb S). Hb S causes the RBC to become hard, sticky and sickle shaped making them fragile and easily destroyed (Youngson, 2000). Unlike normal RBC which are usually smooth and

elastic, sickled cells cannot go through the small blood vessels thus causing blockage and depriving body organs of blood and oxygen. This results in chronic slow deterioration of multiple organ systems culminating in recurrent episodes of severe pain, anaemia, serious infections and damage to vital organs. Further complications include stroke, kidney damage and respiratory problems (Youngson, 2000). The recurrent pain and complications caused by the disease, leads to frequent health facility visitations and hospitalizations which can interfere with many aspects of patient's life as well as that of their families. The families as well as the children affected with SCD, experience a wide range of problems.

Being a chronic and an incurable disorder, the family of affected children experiences distress, anxiety, guilty feelings, social withdrawal and depression which have an impact on the rest of the family and are associated with lower levels of family cohesion (Thompson, Gill & Burbach, 1993).Patients with SCD endure frequent and prolonged bouts of pain and may require multiple hospitalizations to address pain and other SCD complications. Acute painful events known as Crisis, is an important part of the care burden of the caregivers and families of children with SCD.

The morbidity of a painful crisis event and other complications that brings a child to medical attention. does not end once the child is discharged from hospital. Children experience persistent pain even at home after discharge from medical treatment (Shapiro, Dinges, Orne & Frempong, 1995). It is difficult to provide support for crises that may occur at any time of the day or night and that are unpredictable (Moskowitz,Butensky, Harmatz,Vichinsky,Heyman & Acree, 2007). This causes a burden of misery.

In view of the burdens and the impact SCD has on patients and families, the WHO at its fifty ninth (59^{th}) assembly in January 2006, recommended that SCD be acknowledged as a public health issue and emphasized that there is urgent need to establish simple cost effective high strategies, to reduce the morbidity and mortality associated with SCD in countries most affected with SCD (WHO 2006). Countries worldwide are encouraged to strengthen or set up National

programmes which focus on: advocacy, prevention, comprehensive care, counseling, neonatal screening for sickle cell trait linked to timely diagnostic testing, early detection and treatment, parental education, research and community education and partnership (WHO 2006).

Efforts are being made towards the management of SCD in many parts of the world, Africa inclusive. Individual countries worldwide have been making efforts to put in place programmes to educate the public, implement service programmes, encourage research and empower persons living with SCD and their families in order to reduce the encountered problems. In Africa, the WHO Regional Committee for Africa, at its fifty fifth (55^{th}) sessions in September 2005 reviewed the report, *les premier etats generaux de la drepanocytose*, from a meeting in Brazzaville Congo in June 2005 attended by experts and first ladies from five African countries (WHO 2006). The regional committee took cognizance of the meeting subject and declaration and reaffirmed that SCD is an important public health problems.

The executive board of the WHO Regional Committee for Africa at its hundred and seventieth (117^{th}) session in January 2006, concerned about the impact of SCD, adopted resolution EB 117R3, which urged member states to develop, implement and reinforce comprehensive National integrated programmes for the prevention and management of SCD (WHO 2006). They discussed the way forward and suggested what countries and their partners can do to ensure that morbidity and mortality from the disease in infancy and early childhood is markedly reduced. Some of the way forward suggested included creation or strengthening of National SCD control programmes within the framework of National programmes for prevention and control of non communicable diseases, formation of multidisciplinary teams involving health professionals, social workers, patients, teachers, parents, media, interested groups and concerned non governmental organizations to work on the practical aspect of implementing and monitoring SCD health programmes.

Furthermore, the United Nations (UN) at its 63rd General Assembly in December 2008, recognized SCD as a public health concern and underlined the need to raise awareness of the disease at National and International levels by observing the World SCD day on the 19th June of each year. The assembly further encouraged member states in which SCD is a public health concern to establish National programmes and specialized centers for the management of the disease (UN 2008).

In Zambia some efforts are being made to address the burden of caring for children with SCD. In December 2006 physicians from University Teaching Hospital (UTH) Lusaka, met with counterparts from Brigham and women's hospital Boston, United States of America (USA) to discuss the way forward in an effort to try and improve the care, management and reduce the burden of SCD on families (Stossel, 2006).They proposed to establish a Zambia based SCD clinical research center with the aim improving the care and management of patients with SCD.

1.2 STATEMENT OF THE PROBLEM

In Zambia SCD is a common public health problem. It is estimated that 174 of every 10,000 births is to a child with SCD (Athale & Chintu 1994). It is one of the most prevalent chronic genetic blood diseases with frequent episodes of hospitalization in many hospitals in Zambia, including UTH. The annual prevalence rate of SCD in Zambia is 22,051 per 11,025,690 population, while the incidence rate is 2,918 in a population of 11,025,690.

(www,cureresearch .com/sicklecellanaemia/stats-country.htm).

According to the available published data, children with SCD for the years 1993 to 1994 accounted for 938 out of 31,843 total admissions, of children at UTH. Deaths from SCD accounted for 62 out of 6,424 total deaths of children during the same year. Fifty four (54 %) of deaths of SCD children occurred in children below 5 years (Athale & Chintu, 1994). The common causes of death were infections (29%), vaso -occlusive crises (22%), and splenic sequestration crises (20%). The problem of sub Saharan Africa, like malaria, malnutrition and HIV

also added to the mortality. UTH has a SCD clinic which started in 1973 with the aim among others of diagnosing SCD, treatment of both inpatient and outpatient. Over 800 patients have been registered with the clinic (Stossel, 2006).

The above statistics however are no representative of the severity of the problem as it is because only referrals come to UTH while many more patients are attended to at hospitals and clinics in other parts of the country. Since in most rural areas in Zambia access to health centers is often a challenge, most deaths occur away from the health facility and remain undocumented.

Despite all the measures and strategies proposed for alleviating burdens of SCD, the support and management of people living with SCD and their families in Zambia, remains a neglected problem. SCD continues to have devastating effects on both the patients and affected families. In assessing SCD, no one should underestimate the problems experienced by families of affected children. The problems associated with SCD are multifold. The patient and family endure emotional and psychological strain associated with such a chronic incurable disease. They also experience social isolation and stigma surrounding the disease. This social isolation and withdrawal adds to the already existing psychological strain. Financially the families face economical challenges and burdens associated with long hospitalizations and medical expenses.

It is important to take cognizance that management of SCD does not just involve treating medical complications but also alleviating the psychological, social and economical burdens experienced by families. Unfortunately the prevailing situation as it is in Zambia, leaves both new and old cases of SCD patients and their families with no efficient and effective source of psychological, social and economical support in management of SCD. This is partly because there are no established deliberate National SCD programmes, health policies, and well established associations or projects that are aimed or targeted towards SCD. As a result more than 50% of the children with the disease die before the age of five usually from infection, severe anemia and other complications associated with SCD (Athale &Chintu, 1994). The Zambian SCD Association which was

established in 1986 has for several years now not been functioning due to lack of support and commitment. Overshadowed by HIV AIDS epidemic, Malaria, Tuberculosis and Malnutrition, not much has been done on SCD and it still remains largely ignored in Zambia (Stossel, 2006).

It is therefore, important to investigate and establish the problems encountered by immediate families in caring for children affected with SCD in order to help improve the situation. Although no cure exist for SCD, comprehensive programmes for prevention, management, care, support at all levels, family assistance, public awareness, could ensure that the morbidity and mortality caused by the disease is greatly reduced and result in both improved quality of life for both patients and their families.

1.3 FACTORS INFLUENCING THE PROBLEMS ENCOUNTERED BY IMMEDIATE FAMILIES IN CARING FOR CHILDREN AFFECTED WITH SCD

They are several factors that influence the problems encountered by families of affected children. These can be classified into three broad categories as discussed below.

1.3.1 SERVICE RELATED FACTORS

1.3.1.1 Availability of health staff

Availability of health staff at all levels of health facilities, determines the quality of management and Information, Education and Communication (IEC) given to the affected child as well as the family members. If these services are of good quality, it may help lessen the frequency of hospitalization which may be as a result of poor management at home due to lack of support and proper information. This in turn influences the psychological, social and economical problems on the families of affected children.

1.3.1.2 Attitude of health staff

At times the attitude of health staff is that of being rude and unapproachable. As result patients may fear to ask for information and advice from the health staff. Patients and families of the affected children with SCD require a lot of support, advice and IEC from the health staff. Therefore if they cannot access these due to staff attitude it adds more misery and burden to their existing problems.

1.3.1.3 Availability of Genetic Counseling and Screening

Genetic counseling and screening is an important aspect of management of SCD. Its availability can lead to substantial reduction in the number of children born with the disease which will in turn reduce the psychological, social and economic problems of SCD on families of affected children.

1.3.1.4 Availability of drugs

Patients who have SCD require medications time and again such as analgesics for any episodic pain, prophylactic medication, treatment for any infections and other complications associated with SCD (Brandow, Brousseau & Panepinto, 2008). Availability of these drugs will ensure that affected children are managed well and this will results in a reduction of frequent hospitalization. Subsequently this helps lessen psychological, social and economical problems associated with SCD.

1.3.1.5 Availability of diagnostic services

Periodic investigations are necessary to identify and treat early any complications associated with SCD which if left untreated can increase the psychological, social and economical problems of SCD on families of affected children.

1.3.1.6 Availability of IEC materials

IEC provided to families gives an opportunity for quality management of the child both at home and hospital (Brandow et al 2008) .The ultimate goal is to enable them to functionally cope with the child's complex chronic illness and enhance improved quality of life for both the patient and the family (Brandow et al 2008). This knowledge can be passed on to them through IEC given by health

professionals, pamphlets, books, educational programmes in the media and internet among others. Therefore the availability and accessibility to these, has a great influence on the psychological, social and economical problems encountered by the families of affected children.

1.3.1.7 Distance to health facility

The vision of Ministry of Health (MOH) of Zambia is; ***'equity of access to quality, cost effective and affordable health services as close to the family as possible'*** (MOH 2005). However this is not always possible because some families live far away from these services and have to walk long distances or spend a lot of money on transportation to access health services. This is a big challenge to families with children with SCD who require frequent visitations to the facilities.

1.3.1 SOCIAL CULTURAL AND ECONOMIC FACTORS

1.3.2.1 Availability of social support systems

Social support systems are essential in management of SCD. It essential that every child with SCD receive care that is coordinated through multidisciplinary approach in collaboration with health personnel, families and communities.

1.3.2.2 Occupation of parents/caregiver/guardian

Economic status of family influences the care and management of these patients and subsequently influences the psychological, social and economical problems encountered by families of children with SCD. Due to high frequency of hospitalization for persons with SCD, the family incurs expenses that often go beyond the hospital stay. Expenses such as Medical expenses Transport to and from health facilities.

Caregiver or parents may lose income because they need to stay out of work to care for the child at home or hospital. When a family loses income, they end up with problems in household payments such as rent, utilities, Food, school fees and other needs of the family members (Archbold 1993). Therefore occupation of parents /caregivers has a lot of influences on the families of affected children.

1.3.2.3 Cultural beliefs

The cultural /traditional belief towards SCD by the child, family members and community as whole influences the care, management as well as the understanding of the disease. This will in turn influence the extent of the psychological, social and economic burden of SCD on families of affected children.

1.3.2.4 Marital status of parent or caregiver

Families with either single or both parents may either positively or negatively impacts on the families of affected children depending on the prevailing interpersonal relationships within the family environment.

1.3.2.5 Size of immediate family

Depending on the prevailing interpersonal relationships within the family environment, the more or less social, economic and psychological support available to the patient from the family members .This situation will influence the way the child is cared for and comply with the treatment regime.

1.3.2.6 Educational level of care giver

The educational level of care giver influences the understanding of the disease and management of a child with SCD which in turn reduces episodes of hospitalizations due to complications of SCD. Understanding of IEC given by health workers is influenced by level of education and ability to read and write. Therefore level of education has an influence on the psychological, social and economical problems associated with SCD.

1.3.2.7 Stigma

The stigma attached to SCD affects the ability of the family to seek assistance and care. The family may feel ashamed to have a child with a chronic incurable disease. Such stigmatization has a great influence on the psychological, social and economical problems experienced by the family.

1.3.3 DISEASE RELATED FACTORS

1.3.3.1 Fear of the disease outcome

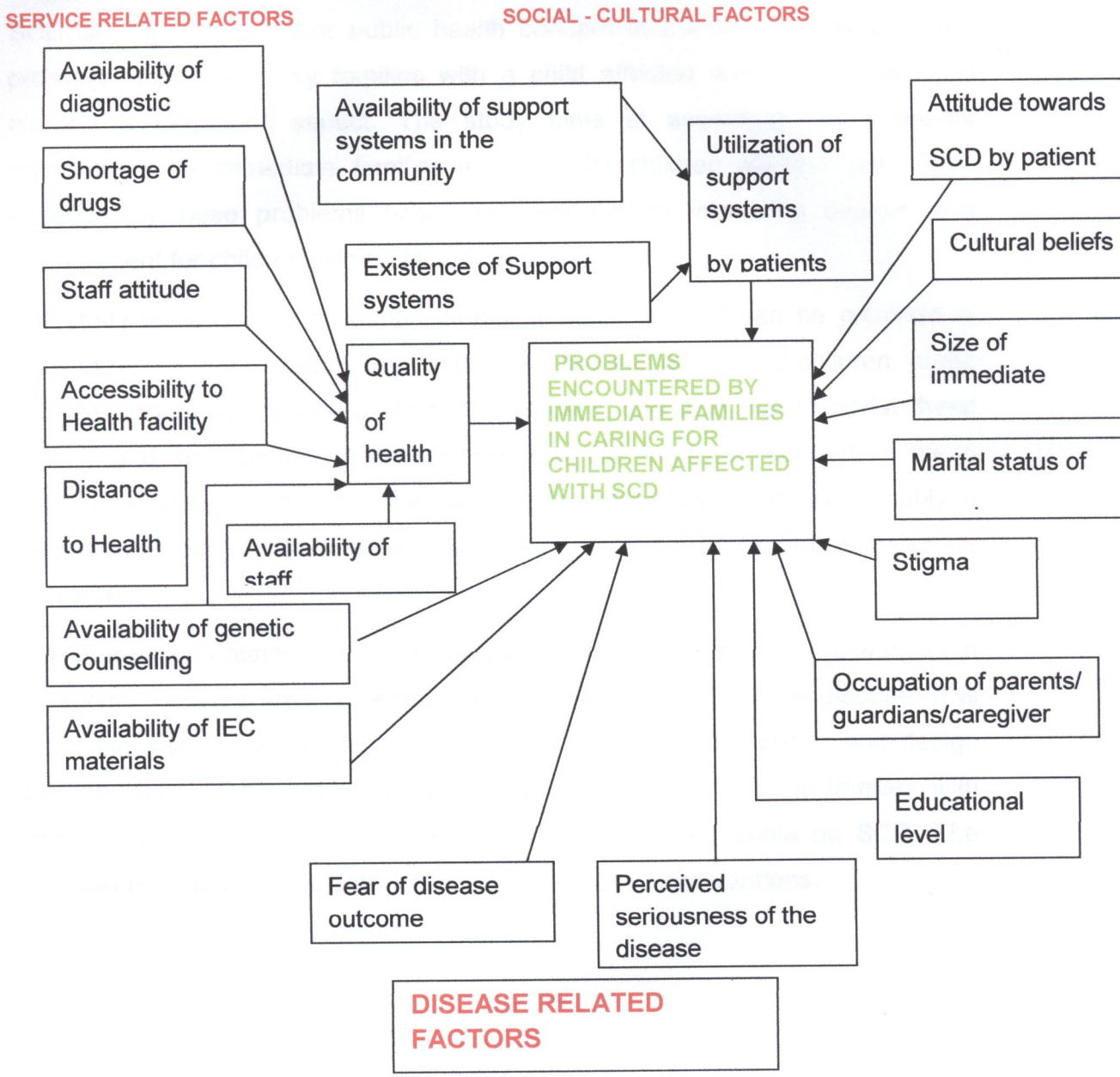
Fear of disease outcome by the child and family members has an influence on the problems encountered by families of affected children. Being a chronic and an incurable disease, they may have uncertainties of the whole disease outcome.

1.3.3.2 Perceived seriousness of the disease

The degree to which the affected child and family members perceive the seriousness of the disease, influences the way they care and manage the affected child. This also influences the problems encountered by the families.

The factors discussed above are further presented in the diagram that follows.

FIGURE 1: DIAGRAM OF FACTORS INFLUENCING PROBLEMS ENCOUNTERED BY FAMILIES IN CARING FOR CHILDREN AFFECTED WITH



1.4 STUDY JUSTIFICATION

SCD has become a major public health concern in Zambia. The burden and problems experienced by families with a child affected with this disease still remains a neglected aspect. The study aims at assessing the problems encountered by immediate families in caring for children affected with SCD. Investigating these problems has great potential for improving support and management for children with SCD.

The study is necessary to identify areas in which support can be provided in order to reduce the problems encountered by families of affected children. Along with the necessary curative and preventive care, one also has to assist these patients and their families in different fields of life. Improved support for these families can make a difference not just in their mental health but also possibly in the physical health of the child and help them enjoy a fruitful and productive life as possible.

The information obtained from this study will be utilized by health care workers in the service delivery area to reduce the problems caused by the disease. It is hoped that the results will help policy makers to formulate policies and design effective strategies to help reduce the problems experienced by families with affected children. Very few studies have been done in Zambia on SCD. The study will provide baseline data for further studies and interventions.

1.5 RESEARCH QUESTION

What problems do immediate families encounter in caring for children affected with SCD?

1.6 RESEARCH OBJECTIVES

1.6.1 GENERAL OBJECTIVE

To assess problems encountered by immediate families in caring for children affected with SCD at UTH paediatrics department children's clinic.

1.6 2 SPECIFIC OBJECTIVES

- To measure level of knowledge on SCD among parents /guardians of children affected with SCD.
- To identify social problems affecting families of children affected with SCD.
- To determine if immediate families experience psychological problems in caring for children affected with SCD.
- To determine economical problems experienced by families of children affected with SCD.
- To assess whether the frequency of hospitalization, monthly family income, levels of knowledge, genetic counseling influences problems experienced by immediate families in caring for children with SCD.

1.7 OPERATIONAL DEFINITIONS

Immediate family: In this study this refers to parents and their children and significant others living in the same household.

Problem: This refers to difficulties experienced by families of affected children as they care for these children.

Psychological factors: This refers to emotional stress experienced by family members of affected children

Social factors: In this study these are factors such friends, interaction with others, encouragement, companionship and interrelationships.

Economical factors: This refers to the financial status of the family under Study.

1.8 RESEARCH VARIABLES AND CUT OFF POINTS

ARIABLE	INDICATORS	CUT OFF POINTS
onomical status of family	High	Monthly income of above K1,000,000
	Medium	monthly income of K 500-1,000,000
	Low	monthly income of less than K 500.000
vel of education of parents/ ardians	High	College or university
	Medium	Secondary
	Low	Primary or no education
cial support available to mily	High	Three or more forms of support.
	Medium	Two forms of support.
	Low	One form of support.
nowledge on SCD	High	Able to answer correctly 4-5 questions on SCD.
	Medium	Able to answer correctly only 1 -3 question on SCD.
	Low	Unable to answer or only answer correctly1 question.
umber of hospitalization in the revious six months	High	More than 6 hospitalization episodes
	Medium	Between 4-5 hospitalization episodes
	Low	Less than 4 hospitalizations

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 INTRODUCTION

Literature review is an organized written presentation on what has been published on a topic by scholars and a presentation of research conducted in your selected field of study (Burns &Grove, 2009).Literature review also refers to activities involved in identifying and searching for information on a topic and developing an understanding of the state of knowledge on that topic (Polit &Hungler, 1999).The literature review used in this study was mainly from primary source which have obtained from journals and online. The focus of literature review was on studies done that are closely related to this topic.

2.2 GLOBAL PERSPECTIVE

A study was done at university of Cincinnati in Ohio by Burlew and Evans (1998). The aim of the study was to assess the impact of SCD on family dynamics. The findings of the research were that primary parent in such a family experiences emotional strain much like parent of children with other chronic illness have been found to exhibit. The research also suggests that the childs presence influences the interpersonal relationships within the family environment. In particular the research suggests that the level of conflict and organization within the family was less favourable than within the control families. The same research also suggests that other factors mediate the impact of the childs illness on the family. In particular, parents with more knowledge about the disease and more social support available appeared to cope more favourably with the illness.

From the above study it is evident that the more psychosocial stressors within the family, the less effectively the patient and the family copes with the illness. In addition the more social support available, the more likely the family is able to cope with the illness.

Moskowitz et al in 2006 conducted a study in California in 2006 entitled "care giving time in SCD: psychological effects in maternal caregivers". In this study maternal caregivers were enrolled as part of a larger observational cohort study to explore the impact of caring for a child with a chronic illness on the primary maternal caregiver. Maternal caregivers, who were the primary caregivers in the home of a child between the ages of 1 and 18 year, were recruited from the patients followed in the haematology department at children's hospital and research centre at Oakland, the University of California. The final sample consisted of 14 maternal caregivers of children with SCD, 44 caregivers of children with HIV and 36 caregivers of healthy children.

The results from the study were that children with SCD had significantly more hospitalization in the previous three months than children with HIV or healthy children. However both the caregivers of children with SCD and HIV spent significantly higher proportion of time in technical care activities than caregivers of healthy children. The study also revealed that although depressive symptoms were high in both caregivers of the two chronic diseases, the care giving burden was higher in SCD associated with the amount of crisis care for the caregivers of children with SCD but not caregivers of children with HIV.

From the above study it is clear that the burden of care in SCD has an impact on the maternal caregiver which in turn has an impact on other maternal responsibilities and needs including care of well children, management of the household, social activities and employment.

Weatherman et al in 2001 conducted a study to examine the burden of inherited disorders of Hb. Their study revealed that the financial burden of caring for a child with SCD came from the cost of life saving procedures such as regular blood transfusions, analgesics and medications such as prophylactic penicillin.

Palermo, Riley and Mitchell in 2008, conducted a study at Oregon health and science university, Portland on "Daily functioning of life in children with SCD pain: Relationships with family and Neighborhood Socioeconomic Distress". The aim of this study was to examine the relationship between individual/family and

neighborhood socioeconomic distress, pain and functional outcomes in children with SCD. The study sample comprised 56 children with SCD aged 8 to 17 years and their caregivers who were recruited from an out patient hematology clinic. The results from this study showed that greater depression was strongly associated with greater pain related disability in both the parent and child. Increased depression correlated with increased disability.

The study revealed that family income was a strong predictor of child reported functional disability with higher income being associated with less disability .The findings demonstrated a relationship between family income and child reported functional disability. It was also found that parent education was significantly associated with both physical and psychosocial Health Related Quality Of Life (HRQOL). Higher parental education was associated with better child physical and psychosocial HRQOL. It was revealed that residing in an economically distressed neighborhood contributes to decreased functional outcomes.

From the above study it is evident enough that, psychological, social and economical factors such as depression, family income, educational level of parents and neighborhood socioeconomic status has a great influence on the increased functional disability and problems encountered by families of affected children.

In Canada Famuyiwa conducted a study on black population on the burden of SCD on families of patients in a naturalistic setting. Families of patients with SCD aged 12years and below were enrolled in comparison with matched groups of epileptic patients, the study revealed that families with a child with SCD experienced more financial expenses incurred in medical care . the families also experienced more sense of despair regarding expectation of crisis, sleeplessness, frustration and abandonment of joint family activities .these were the common cause of burden.

In the United Kingdom, Kofi (2005) conducted a review on Psychological Complications in SCD. The main objective of the review was to examine the evidence for psychological complications with the focus in three key areas

namely: psychological coping, quality of life and neuropsychological problems. The conclusion from this review was that psychological complications in patients with SCD are common. They range from inappropriate coping strategies, reduced HRQOL as a result of negative mood, depression, anxiety, social withdrawal, aggression, poor relationships, and overprotection, excessive feelings of responsibility and guilt, and poor school performance.

A study was done in Netherlands by Tweel &Hatzman in 2008.The aim of the study was to evaluate the Quality of life of female caregivers of children with SCD. The study sample comprised of 99 participants who were mothers of children with SCD who visited the outpatient clinic of the study center. It was revealed that caregivers of children with SCD have significantly lower quality of life and experienced depressive moods, sleeping difficulties, lower vitality and happiness. They also expressed feelings of guilt about the illness of their child and the risk of having another child with SCD had a negative effect on mood. It was also found that low socio-economic status was an additional strain on the caregivers.

From the above study it clearly indicates that SCD has major psychosocial and economic impacts on the caregivers of the affected children.

2.3 REGIONAL PERSPECTIVE

Ayinmode conducted a study at University of Ilorin Teaching Hospital Nigeria in 2007. The title of the study was "psychosocial impact of SCD on mothers of affected children seen at university of Ilorin Teaching Hospital Nigeria". The objective of the study was to assess the psychosocial impact of SCD on mothers of affected children and two control samples. A cross sectional control study design was used. The study sample consisted of 100 mothers of SCD affected children, while the controls were made of 75 mothers of children with bronchial asthma and 75 children of mothers with some acute medical illness.

The results of the study were that 85% of the mothers of children with SCD significantly reported burden in the area of finance, time consumption and hindrance from enjoyment of lives and were more likely to over protect their

children. In this study a total of 28% of SCD mothers were identified as probable cases with psychological problems compared to 20% and 25% of mothers of asthmatics and acute medical illness children respectively. As a result of the prevalent psychological, social and economical impact of SCD, it was strongly suggested that special consideration in terms of the routine psychosocial assessment and treatment be incorporated into various levels of health care system. There is also the need to encourage the establishment of more social organizations like SCD clubs where affected families can interact and counsel one another.

Ohaeri & shokunbi in Nigeria conducted a study to assess severity of economical and psychosocial burden among relatives of 24 SCD patients in comparison with relatives of 24 relatives of patients with other medical conditions. Financial burden of SCD was significantly higher than in other conditions .they found that the economical and psychosocial burden of SCD was significantly reduced by controlling frequency and duration of hospitalizations.

Their study also revealed that the burdens experienced were associated with educational and occupational attainment. Those with higher educational and occupational attainment experienced less financial burden compared with those with lower attainments.

Another study was conducted in Nigeria by Adeyokunna & Adeyeri entitled "Genetic counseling in SCD Ibadan Nigerian experience" in 1999. The aim was to investigate the effectiveness of genetic counseling for families of children with SCD when this was sought out by a parent. A three and half year follow up of 45 families with at least one affected child from Ibadan community was carried out.

The study found that most of the parents sought advice because of problems concerning their affected child, his management, education, future prospects. And marital problems caused by childs condition.

The study also revealed that, following genetic counseling, one third practiced birth control and thus limited family size. The study concluded giving individual

family given genetic counseling, benefits greatly to the ultimate good of the family and population at large.

2.4 NATIONAL PERSPECTIVE

In Zambia studies and data on SCD and its effects and burdens on the families are not readily available and documented. However a study conducted by Athale and Chintu (1992) at UTH on the effect of sickle cell Anemia on adolescence and growth and development concentrated more on growth and development, reproductive health, educational and career achievements, psychological adjustments. The study was conducted between the periods of October 1991 to March 1992. A total of 144 patients above the age of 10 years were interviewed and examined.

In terms of education, they found that there was a high rate of school drop out, delay in education, sometimes even refusal for schooling. The reasons for these were several such as recurrent illness, parental misconception about the disease, financial restraints and general prejudice about the disease. These factors interfered with the patient's growth, education and personality development. Half (50%) of the patients were mentally adjusted to the disease and had learnt to live with the disease and talk about it freely. However this understanding came after a long struggle and unhappiness as a child. Almost half of the patient populations were extremely bitter about the being SCD patient the reasons being: pain which they suffer frequently, recurrent school absenteeism, inability to take part in active sports, inability to be employed, growth retardation and delay in sexual maturity.

Another study done by Kanfwa (1988) on the effect of SCD on the life of a sickler in UTH, revealed that SCD is one of the common causes of pediatrics readmissions .The readmissions are very costly to both the family and the health care system .The researcher found that the family spent a lot of money on several needs such as medication, food, transport since most of the families lived far away from UTH. The study also revealed that most of the caregivers of the

sicklers who were mostly the mother were unemployed because they had to look after the sick child either at home or when hospitalized.

From these studies there is an indication that SCD has several psychological, social and economical implications on the patients and their families which have not been fully investigated and addressed in Zambia. It is therefore hoped that this study will investigate these problems and provide data which will be useful in improving management, care and support of children living with SCD as well as the affected families. This will help to improve their quality of life and alleviate the burdens associated with the disease. The information obtained from the study will also provide baseline data for future studies.

2.5 CONCLUSION

As shown from all the above studies, psychosocial and economic complications in patients with SCD are common and multifold. They range from reduced HRQOL as a result of depression, anxiety, low moods guilty feelings, economical burdens and many more. It has also been revealed that Management of SCD patients does not just involve treating the crises and other medical complications, but also alleviating the psychosocial and economic burdens experienced by families of affected children. The more social support is available to the families, the less the state of psychological problems experienced.

CHAPTER THREE

3.0 RESEARCH METHODOLOGY

3.1 INTRODUCTION

In this chapter, the methodology used for the study is discussed. Methodology refers to a set of methods and principles used to perform a particular activity, or 'the way that pertinent information will be gathered to answer the research question or describe the phenomena related to the research problem (Dempsey & Dempsey, 2000).

3.2 RESEARCH DESIGN

Research design is the overall plan for addressing a research question including the specification for enhancing the integrity of the study (Polit & Hungler, 1999). This study was a descriptive cross sectional study both qualitative and quantitative in nature. This study design was chosen because it helped to give perspective on the burden of SCD in the study population and will assist in planning of health care and preventive services.

3.3 RESEARCH SETTING

Research setting is the physical location and conditions in which data collection takes place (Polit &Hungler, 1999). It is the location where the study is conducted (Burns & Grove, 2009).The study was conducted at UTH pediatrics department, Lusaka. Data was collected from the parents and guardians attending the outpatient SCD clinic where SCD patients are seen and followed up every Friday. The UTH paediatrics department was conveniently chosen because it receives clients with SCD from other hospitals. Therefore the study captured patients not only from Lusaka but other parts of the country as well.

3.4 STUDY POPULATION

Study population is a particular type of individuals or elements who are the focus of the research (Burns & Grove, 2009). For this study, the study population

comprised of parents and guardians of children affected with SCD. This population was chosen because these are the primary caregivers and were in a better position to know the problems experienced in caring for affected children.

3.4.1 Target population

Target population is the entire set of individuals or elements who meet the sampling criteria (Burns & Grove, 2009). The target population for this study consisted of parents and guardians of children affected with SCD seen at UTH paediatrics department.

3.4.2 Accessible population

This is the portion of the target group to which the researcher has reasonable access (Burns & Groove, 2009). For this study, the accessible population was the target group who were available and willing to participate in the study.

3.5 SAMPLING METHOD

Sampling involves selecting a group of people, events, behaviours or elements with which to conduct a study (Burns & Grove 2009). The Sample for this study was selected from the patients available at the outpatient clinic which is conducted every Friday. The respondents were selected using convenience non probability sampling method. In convenience sampling, respondents are included in the study because they happen to be in the right place at the right time. Researcher simply enters available respondents into the study until they have reached the desired sample size (Burns & Grove 2009). The researchers choose this method because time to collect data and complete the study was limited. Since outpatient clinic is conducted only once per week, all the patients available at every given time were given a chance to be selected and included in the study provided they met the inclusion criteria and were willing to participate.

3.5.1 Inclusion criteria

Inclusion sampling criteria are those characteristics that a subject or element must possess to be part of the target population (Burns & Grove 2009).The inclusion criteria for this study was the parents or guardians of children affected

with SCD aged below 15years of age seen at UTH paediatrics department SCD outpatient clinic. All the parents and guardians available at the clinic were given a chance to be selected and included in the study provided they were willing to participate.

3.5.2 Exclusion criteria

Exclusion sampling criteria are those characteristics that can cause a person or element to be excluded from the target population (Burns &Grove 2009).The exclusion criteria for this study ware those people who had brought the affected child to the clinic, but were not themselves parents or guardians of the child. Also those parents or guardians who were not willing to participate in the study were excluded from participating.

3.6 SAMPLE SIZE

According to the SCD clinic, approximately 200 patients are seen every month. Since data collection for this study lasted for about two months, the study population for 2 months was 400.This constituted the sample population. The sample size was calculated using EPI-INFO statistical software. The expected frequency was set at 85%.The worst acceptable frequency was plus or minus 5 % which is 80% or 90%.For this study plus 5% was used. At 95% confidence interval, the sample size was as follows:

Population size - 400

Expected frequency - 85%
Worst acceptable - 90%

Confidence interval - 95%

Sample size (n) - 132 .With the addition of 10% non response rate the final sample was adjusted as follows: 10% of total sample= 13. Therefore final sample size was: n= 132+13 = 145

3.7 DATA COLLECTION TOOL

Data collection tool is a device used in gathering of information needed to address a research problem (Polit and Hungler 1999). For this study data was collected using semi structured interview schedule using a questionnaire which consisted of both closed and open ended questions. This method was used because of some of its advantages which enabled questions being presented in a consistent manner, therefore less opportunity for bias. The questionnaires enabled the researcher obtain data from large number of subjects. The questionnaires were also used to collect both quantitative and qualitative data by use of open ended and closed ended questions in the same questionnaire. The interviewer was present to clarify ambiguous or difficult questions for the respondents and the response rate was higher since the interviewer was available to enter the data on the questionnaire.

However the questionnaire also has some disadvantages such as the presence of the interviewer hindering the respondent to give detailed information. This was taken care of by assuring the respondents of confidentiality, anonymity and also developing good rapport by explaining to them the nature and purpose of the study so as to gain their cooperation and trust.

The semi structured interview schedule for this study had some questions constructed with reference made to some validated tools to help assess the problems encountered by families. These tools include Flanagan's (1998) Quality of Life 16 Item Scale and the WHO (1997) Quality of Life BREF scale. These questions from the tools were modified to suit the study and also had follow up open ended questions to elicit more detailed information.

3.7.1 Validity

Validity refers to the degree to which an instrument measures what it is intended to measure (Polit & Hungler, 1999).To ensure the validity of the research instrument, the questionnaire included each variable under study, and had both closed and open ended questions to give respondents a chance to air their view and express opinions. The questionnaire was checked by research supervisors.

3.7.2 Reliability

Reliability denotes the consistency of measures obtained in the use of a particular instrument (Burns &Grove, 2009).In this study reliability was assured by conducting a pilot study using the questionnaire to pre test it for reliability. Research assistants were also trained to ensure uniformity in data collection, completeness and accuracy in filling of the questionnaire.

3.8 DATA COLLECTING TECHNIQUE

Data collection technique refers to the method used to systematically gather information relevant to the research purpose or the specific objectives, questions or hypotheses of a study (Burns &Grove, 2009). In this study, Privacy was ensured during data collection by using the available rooms to conduct the interviews. The researcher and assistants interviewed the subjects face to face using the structured questionnaire. As many as feasibly possible of the target population available during the clinic day, were interviewed. This exercise continued on subsequent clinic days until the required sample size was achieved. Confidentiality was assured to the respondents and their consent was obtained before commencing the interview. Data collected was only accessible to the researcher and the assistants.

3.9 PRE TEST

A pre test is used to determine whether data collection tools actually measure what they are supposed to measure and is used on subjects who meet the criteria for the study sample (Basavanthappa, 1998).

Pre test for this study was done at UTH paediatrics in patient department in haematology ward. This sample for pre test was chosen because it had similar characteristics to that of the study population. The sample for the pre test was 14 respondents (10% of the entire sample size) and these were selected conveniently from the parents, guardians and caregivers available. Thereafter appropriate adjustments were made to the data collection tool.

3.10 ETHICAL CONSIDERATIONS

Ethical clearance was obtained from the Research Ethics Committee of University of Zambia. Permission to conduct the study was obtained from UTH management.

The purpose and nature of the study was explained to the respondents and written consent obtained. Respondents were not subjected to any physical harm since the study did not involve invasive procedures.

Confidentiality and anonymity was assured to the respondents and no names appeared on the questionnaire. Only codes were used. This was maintained throughout the study analysis and report.

CHAPTER FOUR

4.0 DATA ANALYSIS AND PRESENTATION OF FINDINGS

4.1 INTRODUCTION

Data Analysis is the systematic organization and synthesis of research data and testing of the research hypothesis using those data (Polit &Hungler, 1997). Data was collected using a semi structured interview schedule which consisted of both open ended and closed ended questions. A total of 145 respondents were interviewed giving a response rate of 100%. The data was collected from the parents and guardians of children affected with SCD attending the Out Patient clinic at University Teaching Hospital, Lusaka.

4.2 DATA PROCESSING AND ANALYSIS

Data analysis entails reducing, organizing and giving meaning to the data (Burns &Grove, 2009). After data collection, the researcher sorted the interview schedules and edited them for internal consistence, completeness, legibility and accuracy. Closed ended questions in the interview schedule were assigned numerical codes for easy entry and analysis. Coding is the process of transforming data into numerical symbols that can easily be entered into the computer (Burns &Grove, 2009).

When processing open ended questions the investigator read through the data in its entirety to identify the group answers that belong together. This process is known as categorization (Polit &Hungler, 1997).The groups were then assigned numerical codes. The codes were then entered and analyzed using Statistical Package in Social Sciences (SPSS) version 16. Chi-square was used to compute association. Only a p value of 0.05 or less was considered statistically significant. Findings are presented using tables, graphs and pie charts.

Chi square test was used to test association between variables. The variables included knowledge on SCD, level of education for parents and guardians, frequency of hospitalizations, economic status of family, social support.

The cut off points for statistical significant was set at 5%. Only *P* values of less than or equal to 0.05 were considered significant.

4.3 DATA PRESENTATION

Research findings have been presented using frequency tables, Bar charts, graphs, pie charts and cross tabulations. Cross tabulations are helpful in demonstrating relationship between variables. A variety of data presentations were used to avoid monotony in data presentation. The findings have been presented according to the sections of the interview schedule.

SECTION A

TABLE 1: DEMOGRAPHIC DATA OF RESPONDENTS AND AFFECTED CHILD

VARIABLE	FREQUENCY	PERCENTAGE	VARIABLE	FREQUENCY	PERCENTAGE
AGE			**EDUCATIONAL LEVEL OF CHILD**		
15-24 years	20	14	None	120	83
25-34 years	100	69	Preschool	3	2
34-44 years	15	10	Grade1-4	14	10
45 years and above	10	7	Grade 5 -8	8	5
TOTAL	**145**	**100**	**TOTAL**	**145**	**100**
OCCUPATION			**MARITAL STATUS**		
House wife	69	48	Single	21	15
Student	9	6	Married	74	51
Formal employment	38	26	Divorced	32	22
Self employed	27	19	Separated	6	4
Unemployed	2	1	Widowed	12	8
TOTAL	**145**	**100**	**TOTAL**	**145**	**100**
EDUCATIONAL LEVEL OF RESPONDENTS			**AGE OF CHILD**		
None	36	25	Below 1 year	9	6
Primary	66	46	1- 3years	96	66
Secondary	28	19	4-6 years	26	18
College	14	9	7-8 years	6	4
University	1	1	10 years and above	8	6
TOTAL	**145**	**100**	**TOTAL**	**145**	**100**
MONTHLY INCOME			**RELATIONSHIP TO CHILD**		
K5000.000 and above	20	14	Mother	132	91
K500.000–k400,000	59	41	Father	9	5
K300.000-k2000.000	34	23	Sister	2	2
K1000.000 and below	32	22	Brother	2	2
TOTAL	**145**	**100**	**TOTAL**	**145**	**100**
SEX			**NUMBER OF CHILDREN**		
Male	11	8	1-4	127	88
Female	134	92	5 and above	18	12
TOTAL	**145**	**100**	**TOTAL**	**145**	**100**

Table 1 shows that majority of the respondents 69% (100) were aged between 25-35 years. 134(92%) were females and 11(8%) were male.

Majority of the respondents 88% (127) had between one to four children and 12% (18) had five children and above. Majority of the respondents 91% (132) were the mothers to the affected child, 5% (9) father, 2% (1) sister and 2% (1) brother.

Most of the respondents 51% (74) were married, 22% (32) were divorced, 15% (21) were single, 8% (12) were widowed and 4% (6) were separated.

Most of the respondents 46% (66) had attained primary education, 19% (28) secondary, only 1% (1) had attained university level 9%(14) had attained college education and 25% (36) did not have any formal education.

Most of the respondents 48% (69) were housewives, 26% (38) were in formal employment,19% (27) were self employed, 6% (9) were students and 1% (2) were unemployed.

Majority of the respondents 86% (125) had a family income of below K500.000.00, and 14% (20) had an income of above K500.000

Majority of the affected children 66% (96) were aged 1 to 3 years, below 1 year 6% (9), 4 to 6 years 18% (26), 7 to 9 years 4% (6) and 10 years and above 5% (8).

Majority of the affected children 83% (120) did not go to school, 10%(14) were between grade one and four, 5%(8) were between grade five to eight and 2% (3) were in preschool.

SECTION B

KNOWLEDGE ON SICKLE CELL DISEASE

FIGURE 2: DEFINITION OF SICKLE CELL DISEASE (n =145)

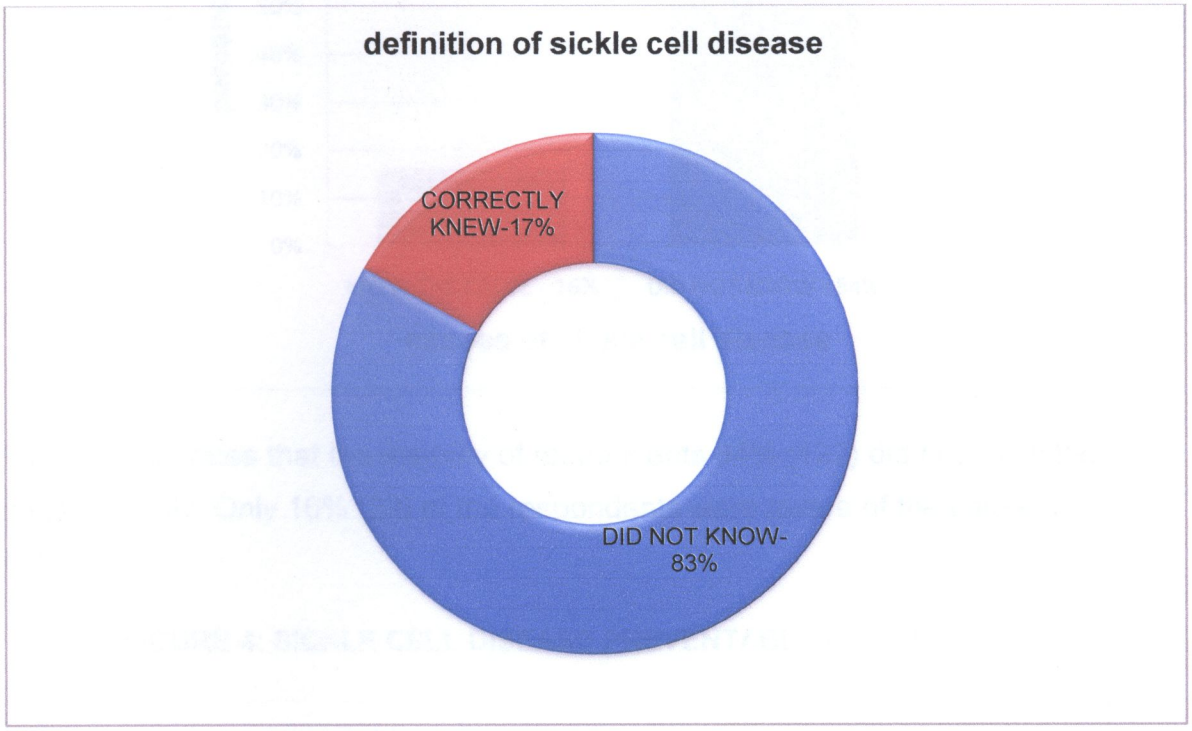


Figure 2 shows that majority of the respondents 83% (120) did not correctly know what SCD was, while only 17% (25) correctly knew what it was.

FIGURE3: CAUSES OF SICKLE CELL DISEASE (n =145)

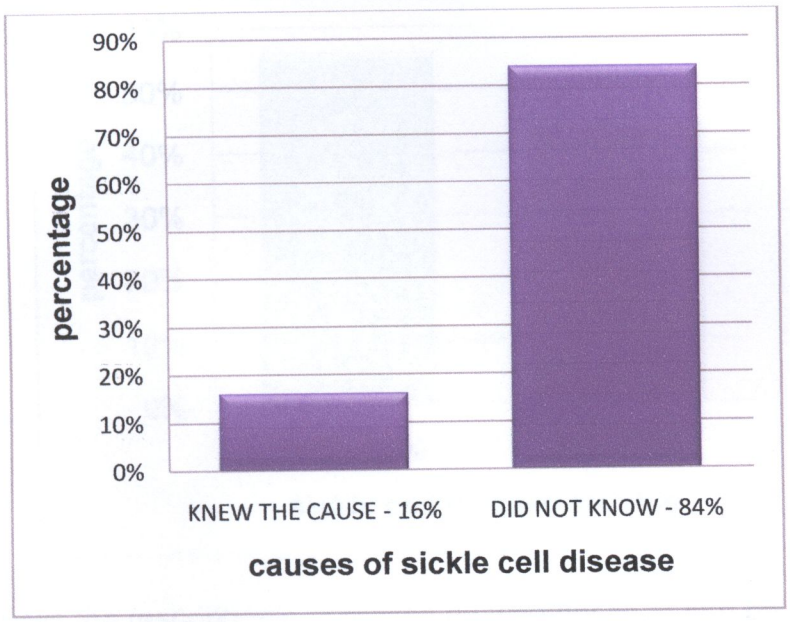


Figure 3 illustrates that the majority of respondents 84% (122) did not know the cause of SCD. Only 16% (23) of the respondents were aware of the cause of SCD.

FIGURE 4: SICKLE CELL DISEASE PREVENTABLE (n =145)

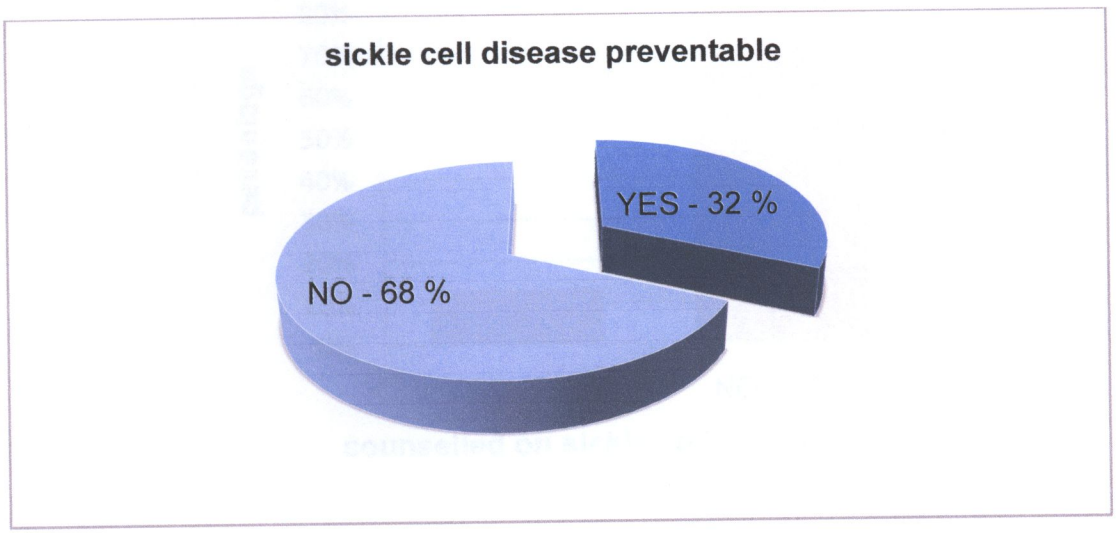


Figure 4 shows that 32% (47) respondents stated that SCD can be prevented while 68% (98) said it cannot be prevented.

FIGURE 5: SICKLE CELL DISEASE CURABLE (n =145)

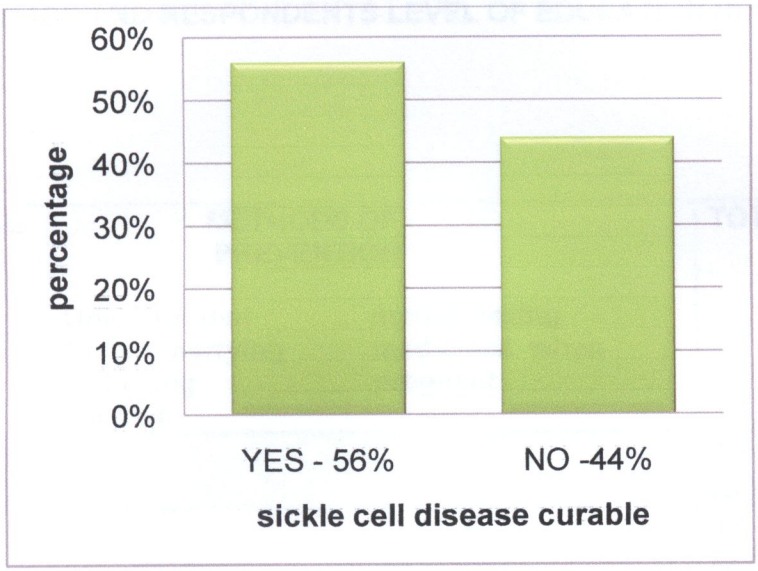


Figure 5 shows the respondents response on whether SCD can be cured. 56% (81) respondents said no, while 44% (64) respondents said it can be cured

FIGURE 6: SPOUSES JOINTLY COUNSELLED ON SICKLE CELL DISEASE (n=95)

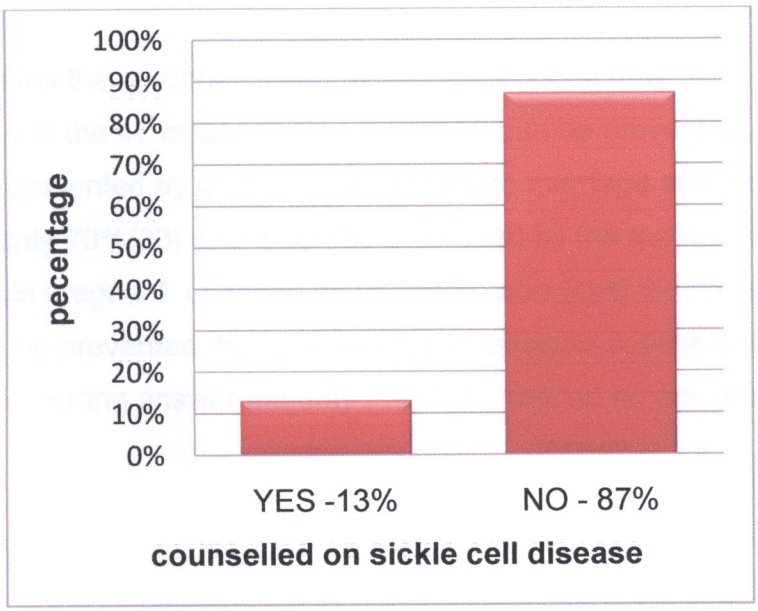


Figure 6 shows that those respondents who had spouses, 13 %(12) had been jointly counselled on Sickle Cell Disease while the majority 87 %(83) reported that had not.

TABLE 2: AN ASSOCIATION BETWEEN PREVENTION OF SICKLE CELL DISEASE AND RESPONDENTS LEVEL OF EDUCATION (n =47)

EDUCATIONAL LEVEL	METHODS OF PREVENTION		TOTAL	*P* value
	Going for test Before marrying Or having children	mother taking medicines when pregnant		0.02
NONE	1	14	15 (32%)	
PRIMARY	2	8	10 (21%)	
SECONDARY	3	6	9 (19%)	
COLLEGE	7	5	12 (26%)	
UNIVERSITY	1	0	1 (2%)	
TOTAL	**14(30%)**	**33(70%)**	**47 (100%)**	

Table 2 illustrates the response given by respondents on how SCD can be prevented. Out of the 47 respondents who said it can be prevented, 30%(14) said it can be prevented by going for testing before marriage and having children while the majority 70%(33) said it can be prevented by the mother taking medicines while pregnant. Of those respondents who gave the correct answer on how SCD can be prevented the majority (7) had attained college education, while those who gave wrong answer majority (14) had attained no education.

FIGURE 7: EDUCATIONAL MATERIALS RECEIVED REGARDING SICKLE CELL DISEASE APART FROM HEALTH TALK FROM HEALTH WORKERS (n = 145)

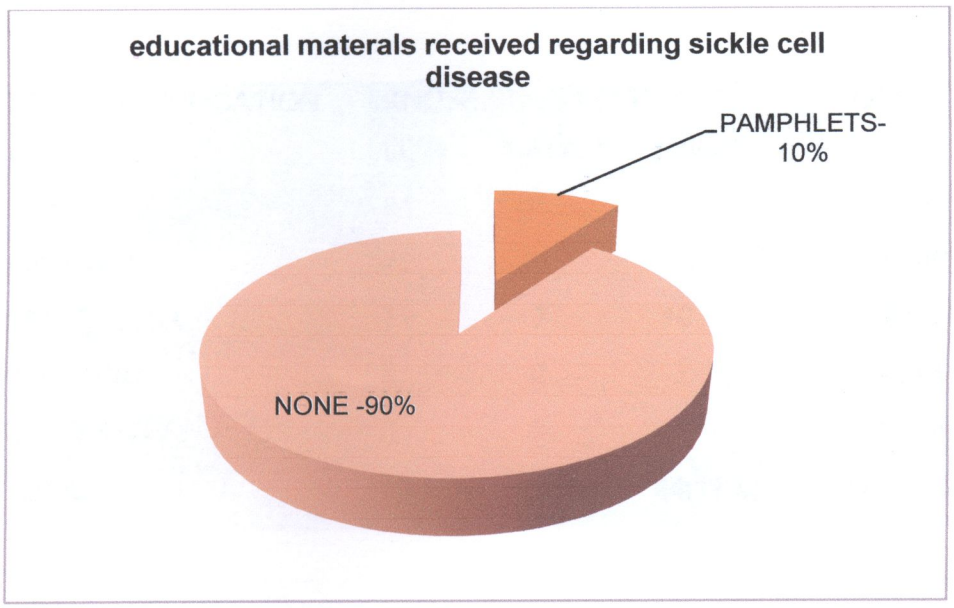


Figure 7 indicates that 90% (130) of the respondents never received any additional informational materials regarding Sickle Cell Disease apart from health talk from health workers, and 10% (15) had received pamphlets.

TABLE 3 : ASSOCIATION BETWEEN EDUCATION LEVEL AND OVERALL KNOWLEDGE ON SCD (n=145)

LEVEL OF EDUCATION	KNOWLEDGE LEVEL			TOTAL	P VALUE
	LOW	MEDIUM	HIGH		0.01
NONE	34	1	1	36 (25%)	
PRIMARY	42	19	5	66 (46%)	
SECONDARY	11	7	10	28 (19%)	
COLLEGE	5	2	7	14 (9%)	
UNIVERSITY	0	0	1	1 (1%)	
TOTAL	**92(63%)**	**29(20%)**	**24(17%)**	**145 (100%)**	

Table 3 shows that majority of respondents 63% (92)had low levels of knowledge on SCD, 20%(29) had medium knowledge and 17% (24) had high knowledge levels .The large number of respondents (76) with low levels of knowledge were those with no education and those with primary education.

SECTION C

ECONOMICAL FACTORS

TABLE 4: AMOUNT OF MONEY SPENT WHEN CHILD WAS ADMITTED IN HOSPITAL (n = 145)

AMOUNT IN KWACHA	FREQUENCY	PERCENTAGE
500.000.00 and above	3	2
400.000.00 to 500.000.00	70	49
200.000.00 to 3000.000.00	69	47
100.000.00 and below	3	2
TOTAL	145	100%

Table 4 shows that majority of respondents 49 %(70) spent betweenK500.00.00 to K400.000.00 when their child was admitted in hospital, 47% (69) spent between K300.000.00 to K200.000.00. 2% (3) of the respondents spent K500.000.00 and above, and 2 %(3) spent below K100.000.00.

FIGURE 8: UNABLE TO WORK DUE TO CARING FOR THE AFFECTED CHILD (n=145)

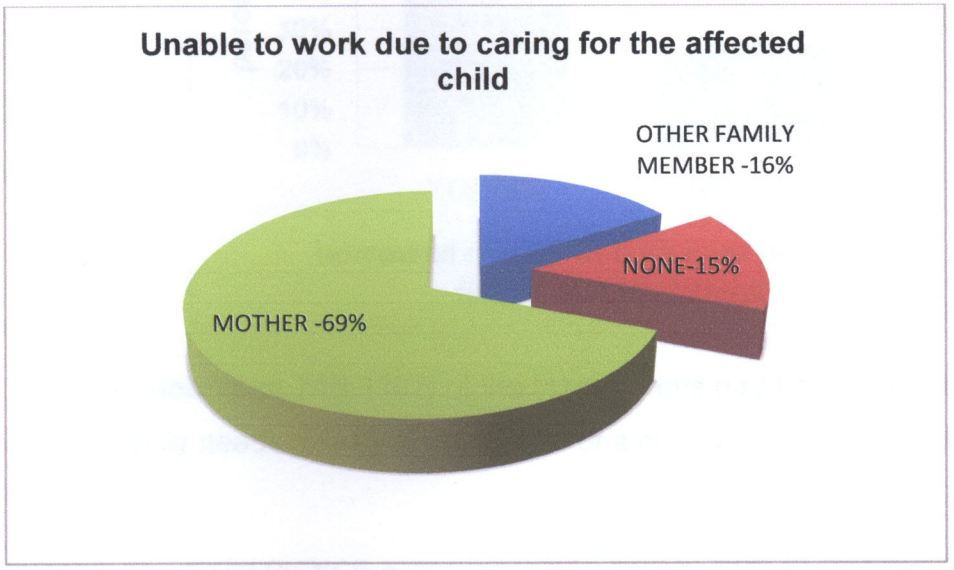


Figure 8 shows that 69% (100) of the mothers were unable to work due to caring for child and 16% (23) of the respondents said the other family members were unable to work. 15% (22) of respondents said that none of the family members were unable to work due to caring for sick child.

FIGURE 9: EVER BORROWED MONEY FOR FAMILY NEEDS (n=145)

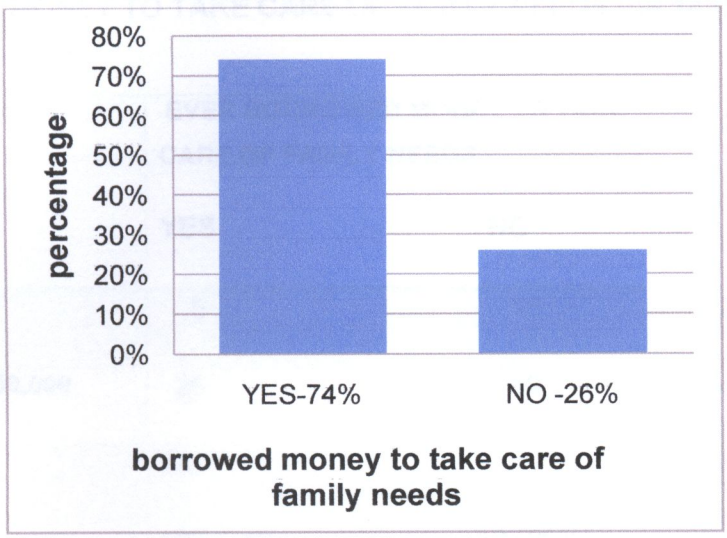


Figure 9 shows that 74% (107) of the respondents had borrowed money to take care of family needs due to the presence of a child with SCD, 26%(38) said they did not.

FIGURE 10: EXPERIENCE ANY FINANCIAL PROBLEMS IN CARING FOR THE AFFECTED CHILD (n =145)

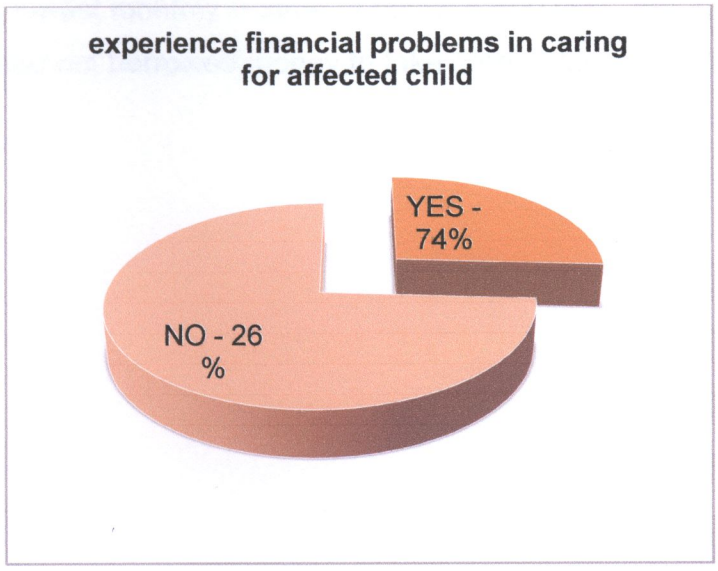


Figure 10 illustrates that 74% (107) of the respondents experienced financial problems when caring for a child affected with SCD while 26% (38) did not.

TABLE 5: ASSOCIATION BETWEEN FAMILY MONTHLY INCOME AND BORROWING MONEY TO TAKE CARE OF FAMILY NEEDS (n= 145)

MONTHLY INCOME IN KWACHA	EVER BORROWED MONEY TO TAKE CARE OF FAMILY NEEDS		TOTAL	P VALUE 0.01
	YES	NO		
ABOVE K 1,000,000	5	15	20 (14%)	
K1,000,000 TO K500,000	26	19	45 (31%)	
BELOW K500,000	76	4	80 (55%)	
TOTAL	**107 (74%)**	**38 (26%)**	**145 (100%)**	

Table 5 shows that 74%107) respondents stated that they had borrowed money to take care of family needs due to presence of a child affected with Sickle Cell Disease. Majority (76) of those who borrowed money were those respondents who had the lowest monthly income of below K 500,000. 26% (38) respondents stated they had not borrowed money to take care of family needs.

SECTION D

PSYCHOLOGICAL FACTORS

TABLE 6: RESPONDENTS FELT DEPRESSED DUE TO LIVING WITH A CHILD AFFECTED WITH SCD (n = 145)

	FREQUENCY	PERCENTAGE
YES	112	77
NO	33	23
TOTAL	145	100%

Table 6 shows that 77% (112) of the respondents said that they felt depressed as a result of living with a child affected with SCD and 23 % (33) did not.

FIGURE 11: NEGATIVE FEELINGS BY PARENTS / GUARDIANS (n =145)

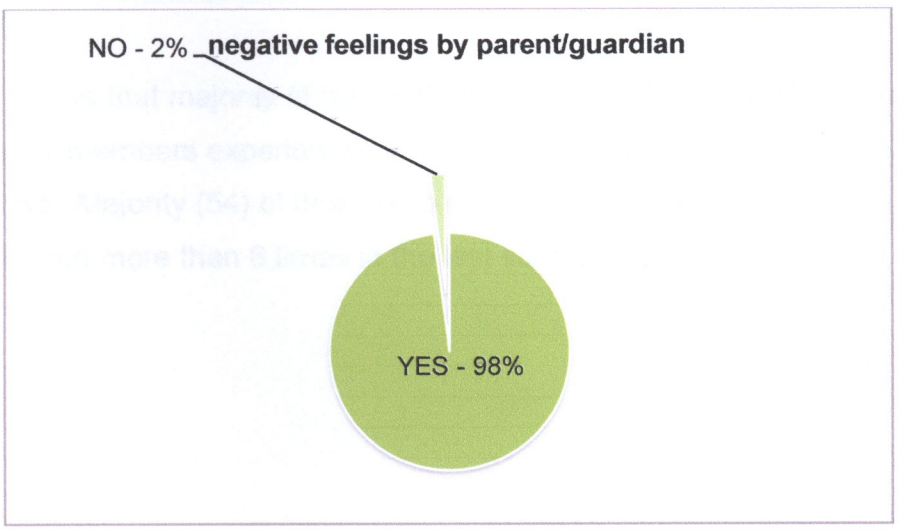


Figure 11 shows that 98% (142) of the respondents experienced negative feelings and 2 % (3) never did.

TABLE 7: AN ASSOCIATION BETWEEN FREQUENCIES OF HOSPITALIZATION AND RESPONDENTS AND THEIR FAMILY MEMBERS EXPERIENCING FEELINGS OF BEING DEPRESSED (n=145)

NUMBER OF HOSPITALIZATIONS IN THE LAST SIX MONTHS	DEPRESSED		TOTAL	*P* VALUE
	YES	NO		0.02
MORE THAN 6 TIMES	54	8	62 (43%)	
4-5-TIMES	36	7	43 (30%)	
LESS THAN 4 TIMES	22	18	40 (27%)	
TOTAL	**112(77%)**	**33(23%)**	**145 (100%)**	

Table 7 shows that majority of respondents 77 %(112) reported that them and other family members experienced feelings of depression, while 23% (33) said they did not. Majority (54) of those who experienced depression had the affected child admitted more than 6 times in the last six months.

FIGURE 12: GUILTY FEELINGS BY PARENT/GUARDIAN LIVING WITH A CHILD AFFECTED WITH SICKLE CELL DISEASE (n=145).

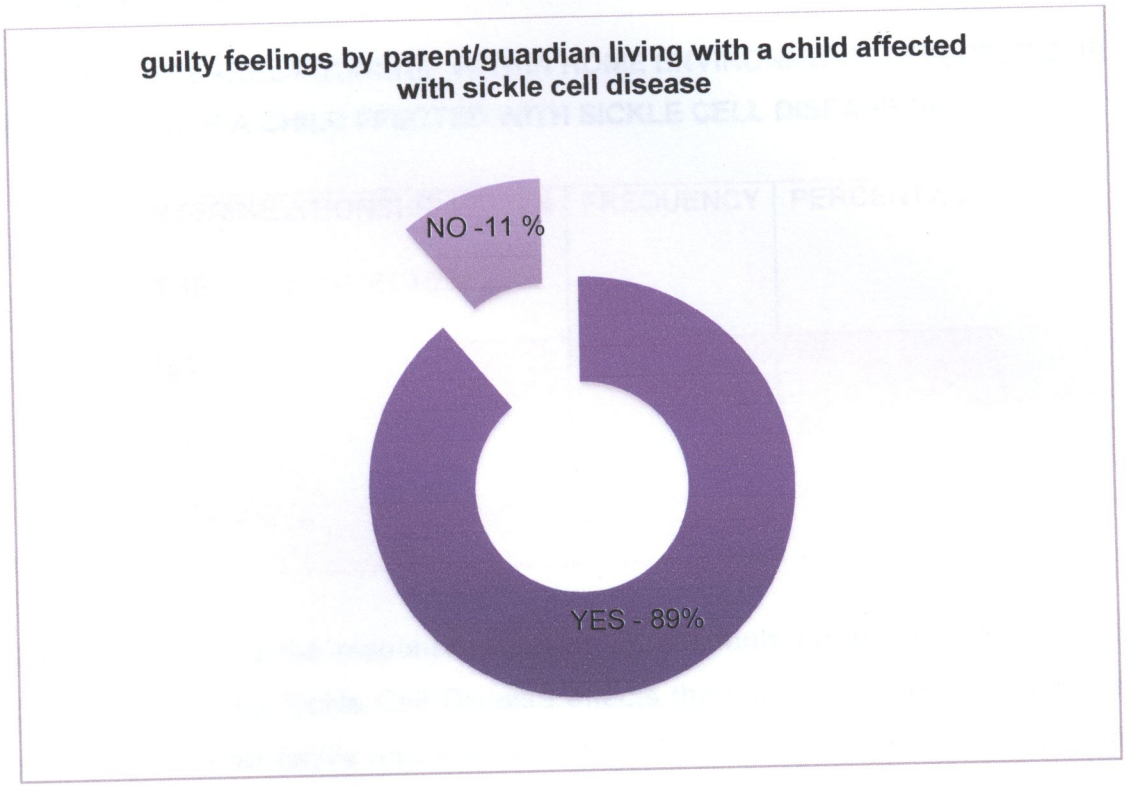


Figure 12 shows that majority of the respondents 89% (129) indicated that they experienced guilty feelings living with a child affected with SCD and 11% (16) did not.

SECTION E

SOCIAL FACTORS

TABLE 8: INTERRELATIONSHIP WITHIN HOME ENVIRONMENT AFFECTED DUE TO LIVING WITH A CHILD FFECTED WITH SICKLE CELL DISEASE (n=145)

INTERRELATIONSHIP WITHIN THE HOME AFFECTED	FREQUENCY	PERCENTAGE
YES	110	76
NO	35	24
TOTAL	145	100%

Table 8 illustrates the response given by respondents on whether living with a child affected with Sickle Cell Disease affects the interrelationship with parents, siblings and other family members within the home environment. Majority of the respondents 76% (110) stated that living with a SCD child affected relationships within the home. 24% (35) said no.

TABLE 9: LIVING WITH A SICKLE CELL DISEASE CHILD AFFECT RELATIONSHIP WITH OTHER PEOPLE OUTSIDE THE HOME (n =145)

	FREQUENCY	PERCENTAGE
YES	124	85
NO	21	15
TOTAL	145	100%

Table 9 shows that majority of the respondents 85% (124) answered affirmative to the above question and 15% (21) answered negative.

FIGURE 13: LIVING WITH A SICKLE CELL DISEASE CHILD AFFECTS RELATIONSHIP WITH SPOUSE (n = 95)

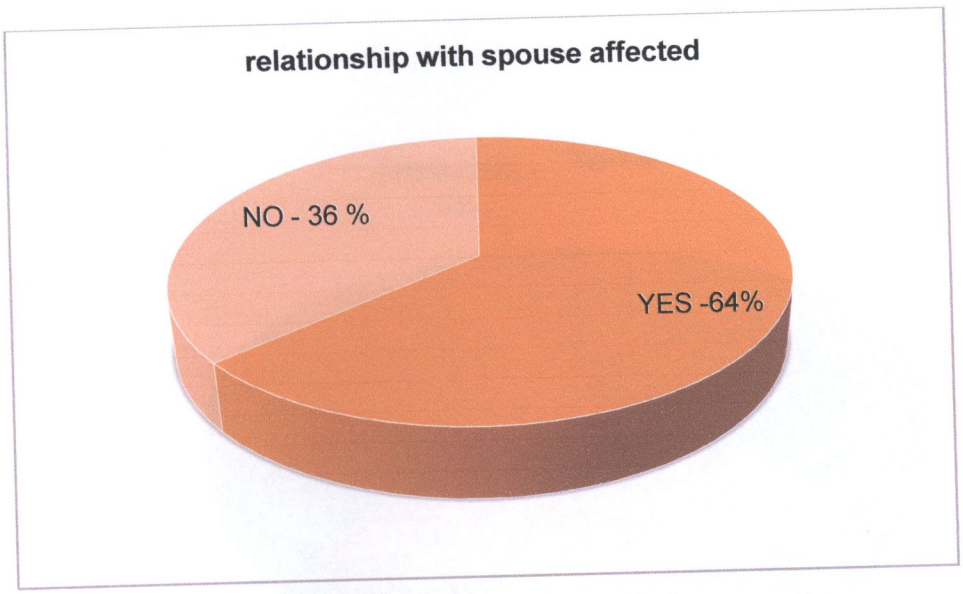


Figure 13 shows that out of the 95 respondents who had spouses majority 64% (61) stated their relationship with spouse was affected and 36%(34) said no.

TABLE 10: ASSOCIATION BETWEEN JOINT COUNSELLING AND RELATIONSHIP WITH SPOUSE AFFECTED (n =95)

RELATIONSHIP AFFECTED	JOINT COUNSELLING		TOTAL	P VALUE 0.01
	YES	NO		
YES	4	57	61 (64%)	
NO	8	26	34 (36%)	
TOTAL	**12**	**83**	**95(100%)**	
	(13%)	**(87%)**		

Table 10 shows that majority 64%(61) of those whose relationship with the spouse affected , they had not received joint counselling.

FIGURE 14: TYPE OF SUPPORT RECEIVED TOWARDS CARE OF CHILD (n= 145)

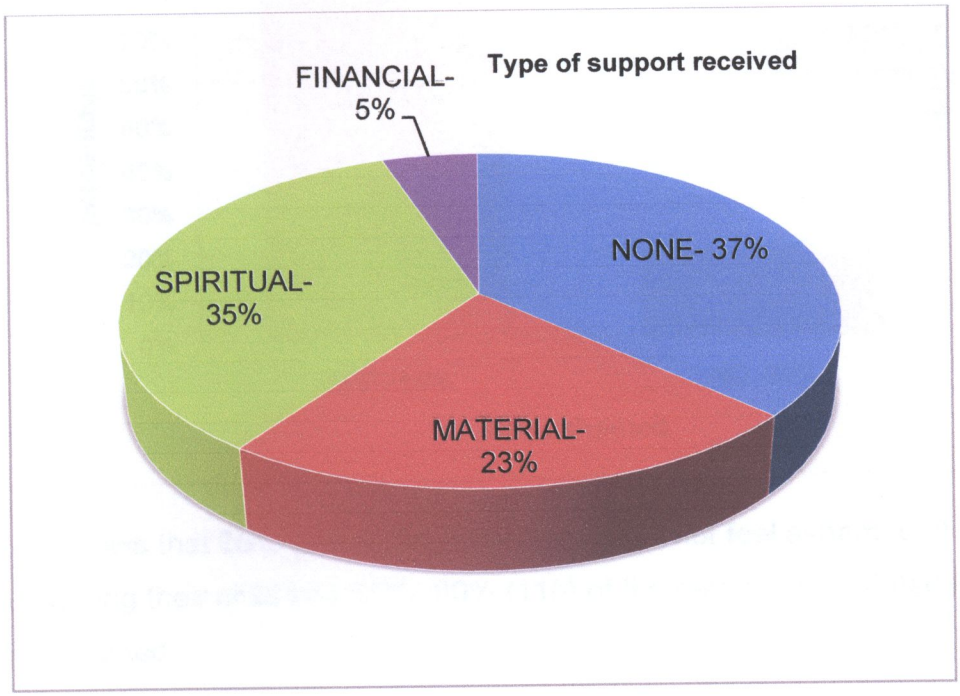


Figure 14 shows the type of support given to respondents towards the care of their child. 37% (54) of the respondents did not receive any type of support towards the care of their child, 35% (50) received spiritual support, 23% (33) received material support and 5% (8) received financial support.

FIGURE 15: PARENT/GUARDIAN FELT ASHAMED OF OTHERS KNOWING THEIR CHILD HAD SICKLE CELL DISEASE (n=145)

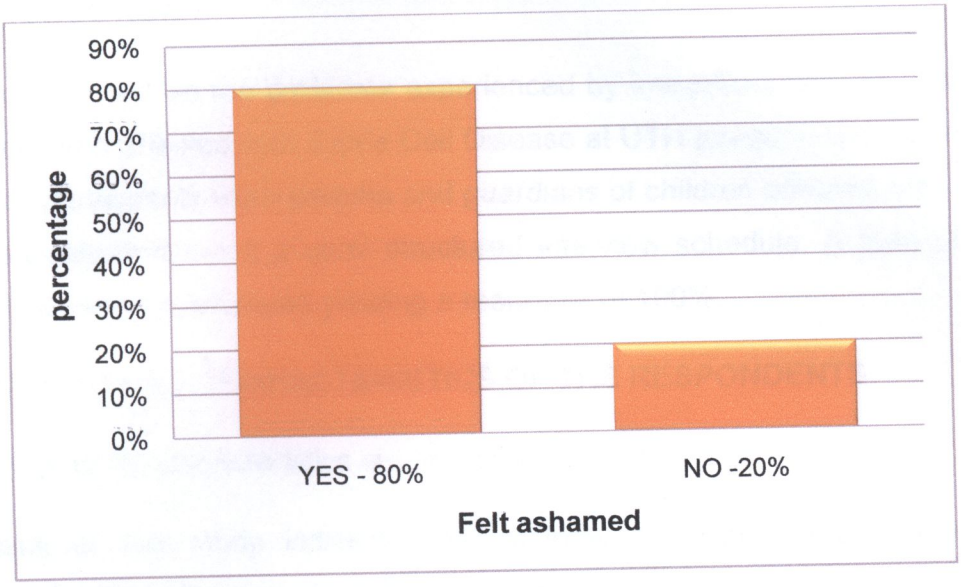


Figure 15 shows that 20% (29) of the respondents did not feel ashamed of other people knowing their child had SCD. 80% (116) of the respondents stated that they felt ashamed.

TABLE 11: EXPERIENCE ANY PROBLEMS WHEN CARING FOR CHILDREN AFFECTED WITH SCD (n=145)

EXPERIENCED PROBLEMS	FREQUENCY	PERCENTAGE
YES	145	100
TOTAL	145	100%

Table 11 shows that all the respondents 100% (145) acknowledged that they experienced problems when caring for the children

CHAPTER FIVE

5.0 DISCUSSION OF FINDINGS

5.1 INTRODUCTION

The study focused on the problems experienced by immediate families in taking care of children affected with Sickle Cell Disease at UTH paediatrics department. The study participants were parents and guardians of children affected with SCD. Data was collected using a semi structured interview schedule. A total of 145 respondents were interviewed yielding a response of 100%.

5.2 DEMOGRAPHIC CHARACTERISTICS OF THE RESPONDENTS

The demographic characteristics are shown in Table 1.

The result of this study indicated that majority of respondents 69% (100) interviewed were in the age group 25-34 years.

The majority of the respondents 88% (127) had between 1- 4 children, 12 %(18) respondents had more than 5 children. The reason for this could be due to the fact that majority of respondents interviewed were in the age group 25-34 years which is sexually active and still child bearing age.

Majority of the respondents 91% (132) were the mothers to the affected child. This could be attributed to the fact that normally the main caregiver is the mother and these are the ones who normally bring the children to the hospital for medical attention.

More than half of the respondents 51% (74) were married. This could be attributed to the fact that most of the women had low levels of education and therefore marriage was a source of socioeconomical support.

Most of the respondents 46% (66) had attained primary school educational and only 7% (1) had university education. The explanation for this could be that the majority of respondents were women who tend not to go very high in their education due to early marriages.

Most of the respondents 48% (69) were housewives. This could be attributed to the fact that majority of the respondents were mothers and these are the main caregivers and they do not work due to care giving responsibilities.

Majority of the respondents 86% (125) had a monthly family income of below K500.000. This could be because majority of respondents were housewives and had no formal employment and no monthly income to contribute to the family.

In this study more than half 66 %(96) of the children affected with SCD were aged between 1 to 3 years. This could be attributed to the fact that according to available data, in Zambia the 50% of children with SCD die before the age of five due to medical complications associated with the disease.

Majority of the children 83% (120) did not go to school because majorities 66% (96) of them were aged below 3 years which is below school going age.

5.3 KNOWLEDGE ON SICKLE CELL DISEASE

When a parent or guardian acquires adequate information on a particular disease, she or he is more likely to effectively take care of an affected child. Having adequate knowledge about SCD is very important. This helps reduce episodes of illness and hospitalizations which may occur due to complications of the disease, arising from poor care and management by care givers.

The research findings showed that majority 63% (92) had low levels of knowledge as they could not answer any or gave only one correct answer when they were asked questions on SCD. Questions included defining SCD in their own understanding, causes of SCD, whether it can be prevented and how, if it can be cured. This could be attributed to the fact that majority of the respondents 70% (102) had either primary education or had attained no education at all and hence they could not easily comprehend educational information on the disease. This study revealed an association between levels of knowledge on the disease and educational level of respondents (p value of 0.01 Table 3).

Education level influences understanding of the disease management of a child with SCD. Understanding IEC also is influenced by level of education and ability to read and write. This is supported by Jensen, Elkin, Hilker, Jordan, Lyer &Smith (2006) in their study entitled Caregivers knowledge and adherence in children with SCD knowing is doing. The objective of the study was to examine the relationship of caregivers' knowledge on SCD and children's adherence to treatment behaviours, such as adequate hydration, folic acid supplementation proper sleep. They found that 72% of caregivers had high levels of knowledge and this was linked with better quality of life and reduced painful episodes.

When the respondents in this study were asked to define SCD according to their own understanding, the majority of respondents 83% (120) were unable to give a correct definition since they said SCD was merely a disease that lessens blood in the body and that it affects several parts of the body such as the neck, legs, joints, back. Only 17% (25) of the respondents could define the term correctly as genetically inherited disease that affects blood in the body.

This study also revealed that the majority of the respondents 84% (122) did not know the exact cause of SCD. Out of these, 54 %(78) reported that SCD came as a result of witchcraft or supernatural powers. 30% (44) did not even know what caused SCD. Only 16% (23) were able to indicate that SCD was a disease that is genetically inherited from both parents. All this is attributed to the low levels of educational achievement by majority of the respondents.

These findings are in contrast with those found by Milosavljevic et al (2007) in their study in Jamaica. They reported that all parents knew what was SCD, and that there is no cure for the disease but that good management is vital in order to avoid complications. They also had knowledge on how to prevent the disease. Their study revealed that their knowledge came from the fact that when attending SCD clinic for the first time, caregivers were given a very clear printed brochure about the disease.

From this study, it is interesting to note that the majority of the respondents 56% (81) reported that that SCD can be cured while 44% (64) stated that SCD cannot be cured. For those who said it could be cured they believed in religious healing as an alternative approach or in addition to routine medical treatment. This may be attributed to the belief that the disease is caused by divine retribution or supernatural powers.

This study revealed that a large number of the respondents 68% (98) indicated that SCD cannot be prevented and 32% (47) stated that it can be prevented. For those who said that SCD can be prevented, 24% (35) reported that it can be prevented by the mother taking medicines while pregnant to avoid giving birth to a child with SCD. Only 8% (12) correctly stated that it could be prevented by going for a test before marriage or having children. An association between educational level and knowing how SCD can be prevented was revealed from this study (*p* value 0.02 Table 2).Testing for SCD is a very important aspect in preventing children being born with the disease. Individuals should go for blood tests before marriage and having children to determine their blood genotype. They should understand that when those with AS (sickle cell trait) blood marry or have a child with a person who also has AS blood, they run high risk of producing a child with SCD.

With regards to source of educational information on SCD all the respondents 100% (145) indicated the source of information was from the health workers. Only 10% (15) of the respondents had received additional information which was in form of pamphlets on SCD. This could be the other reason for the low level of knowledge among respondents in this study. The limited source of information a may sometimes be not sufficient enough for one to acquire enough knowledge. Other sources of educational information are essential. This study revealed that the majority of the respondents 90% (130) had not received any informational materials regarding SCD such as posters pamphlets, books, video tapes and others. This could be due to the fact that these materials are not available in the

health institutions to be distributed to the parents / guardians. This contributed to the low levels of knowledge among the respondents.

Several sources of information are very important in acquisition of knowledge on SCD or any particular disease for that matter. This statement is supported by a study done by Oluwole (2010) in Nigeria. The study aimed at determining the awareness of SCD among the youth in a Nigerian National Service Community. The sample size was 117. The study revealed that the majority of the respondents 97.4% (113) were aware of SCD and had multiple sources of information on SCD such as seminars (30.1 %), health worker (27.4 %), media (19.5%), peer (7.1%), books (6.2%), family members (5.3%) and internet (4.4%).

All these avenues are very important resources of dissemination of information on SCD, given the reality that staffs do not have adequate time to give IEC to patients and clients due to shortage of staff in our health institutions.

When asked whether the respondents were jointly counselled with their spouses on SCD, the study revealed that of 95 respondents who had spouses, the majority of the respondents 87% (83) stated that they had never been jointly counselled with their spouses regarding SCD. Only 13% (12) respondents had been jointly counselled with their spouses. This could be the other explanation for the low level of knowledge among respondents in this study. It is worth mentioning that the importance of genetic counselling in a genetically inherited disease such as SCD cannot be overemphasized. It is through such counselling sessions that all the necessary IEC can be given by health professions to the clients.

The findings of this study on counselling are contrarily to those of Thompson (1996) in Nigeria who found that majority of respondents had undergone counselling on SCD. All those, who had under gone counselling, were all aware that people should undergo blood tests to determine their blood genotype, before they consider marriage or having children. The people understood that those

who had AS blood should understand that if they married a person who also has AS blood they run a high risk of producing a child that will have SCD.

Counselling helps people to make informed choices. It is not intended to frighten people or tell them who they should marry or not. But if counselled and tested, they are in a position not only to make decisions based on knowledge of facts but to prepare themselves mentally to accept the consequences of those decisions.

5.4 ECONOMIC FACTORS

Financial burden of SCD care and management can be a major source of anxieties for the families of children affected with SCD especially if they are poor.

This study showed that most of the respondents 48% (70) spent between K 500.000.00 to K 400.000.00 when the child was hospitalized. The study revealed that this money is mostly spent on food, medicines, transport and investigations. The respondents reported that children with SCD are on prophylactic medications such as iron supplements and antimalarial. These drugs are sometimes not available at the hospital and therefore families have to buy from private pharmacies. They also need regular investigation such as for Hb levels, white blood cell count and platelet counts. Sometimes the hospital laboratories cannot perform these tests due to shortage of reagents. The families end up having these tests done at private laboratories. This is a huge financial strain on the family considering that most of the respondents 55% (80) had a family monthly income of below K 500.000.00.

This finding from this study is similar to the findings of Brown, Okeeke, Lagunju, Orimadueg &Ohaeri (2010) from their study entitled "Burden of health care of carers of children with SCD". They found that in Nigeria where cost of all health services is borne by carers, managing a child with SCD was a source of financial distress to the families.

It is thus not surprising that this study also revealed that the majority of the respondents 74% (107) experienced financial problems and ended up borrowing

money in order to take care of other family needs due to the fact of high expenses experienced in taking care of affected child. This study has revealed a significant association between monthly income and respondents borrowing money (p value of 0.01 Table 5).

This study further revealed that more than half of the respondents 69% (100) mothers were unable to work because of caring for the child. Painful episodes and frequent hospitalizations affect the caregiver's ability to go for work which in turn adversely affects the economic status of the family.

This finding is similar to that of Brandow, Dousseaul & Panepinto (2008) who conducted a study aimed at describing the outcome of children with SCD after discharge from medical care for Vaso-occlusive painful events. The study revealed that painful events affected the caregivers ability to work or attend school which can in turn impact the socioeconomic status of the family. They also found that people of low socioeconomic status were more likely to have jobs that do not give sick leave or feasible work hours that allow them to care for a sick child. This made them miss work days and most of them were unemployed.

When a chronic disease such as SCD occurs in an already impoverished family, the impact of missed work and potential unemployment magnifies the economic burden. This further negatively impacts on the socioeconomic status of the entire family. It is thus worth mentioning that in Zambia 73% of the population is poor and majority of households live below poverty datum level since many of them earn little or no regular income to sustain their livelihood (Mwinga 2002).

According to the Jesuit Centre for Theological Reflection (JCTR), the World Bank estimates that over 80% of Zambians live in households that lack adequate means to meet basic daily needs (JCTR 2000). This kind of situation puts families with children with chronic illnesses such as SCD in more financial burdens.

5.5 PSYCHOLOGICAL FACTORS

A common manifestation of SCD in children is unpredictable episodic pain crisis which leads to frequent hospitalizations. Such children and their families are at risk of development of psychological problems.

This study has revealed that families of children affected with SCD experience several psychological problems. For instance the majority of the respondents 77% (112) indicated that family members experienced depression as a result of living with a child affected with SCD. Out of these 64 of them were mothers who among them 39 stated they felt depressed because of the burden of caring for the sick child and 25 felt depressed because they did not expect to have a child with SCD. The remaining respondents 33%(48) said that the other family members felt depressed because the mother of the child who is usually the main caregiver, often was depressed and that her sadness affected the entire household. An association was noted between frequency of hospitalizations and depression (*p* value 0.02 Table 7).

These findings are similar to those of Tweel,Hartzman,Ensink,Peters, Fijnvandraat & Grootenhuis who in their study entitled "Quality of life of caregivers of children with SCD", found that caregivers of children with SCD had depressive moods and that the risk of having another child with SCD had a negative effect on mood. The respondents in their study were mothers and caregivers of children with SCD who visited the outpatient clinic.

This study revealed that the majority of the respondents 89 %(129) experienced guilty living with a child affected with SCD. The reason given was that because they are the ones who gave birth to this child who was suffering so much all the time. These findings are similar with those of Antle, Williams & Cook (2008) in their study of understanding the experience of mothers raising a child with SCD among African and Caribbean descent living in Canada. Their findings revealed that parents felt guilty to have a child affected with SCD. Some mothers reported that their guilt stemmed from the fact that other people assumed that the mothers knew about SCD gene and their pregnancy and they still chose to conceive an ill

child. The mothers described that this blame contributed to their feelings of guilt about genetically transmitting the SCD trait to their children.

This study revealed that almost all the respondents 98% (142), experienced negative feelings such as blue moods and anxiety quite often. This was due the fact that they felt that the child will not grow but die due to frequent illness episodes and hospitalizations .These findings are similar with the findings of the study of Burlew, Evans & Oler (1998) who found out that parents had emotional reactions which included concern about the future outlook of the child, resentment, anxiety and anger or embarrassment.

Similarly Antle et al (2008) also found that mothers reported fear of the child dying which subsequently lead to feelings of anxiety and isolation. All the mothers in their study also reported living in constant fear that their children might suddenly require hospitalization and could potentially die.

In this study 32% (46) of the respondent said that they experience anxiety and blue moods because they were worried that even though their child had reached school going age, they had not started school due to the illness and frequent hospitalizations. This was a major stressor to the parents who were uncertain what the future would be for their children if they were not educated. For the few children 3% (25) who were school going, their schooling was affected since they missed a lot of school days due to frequent illness episodes.

These findings are consistent with those of Nettles (1994) in his study of scholastic performance of children with SCD which revealed problematic effects of SCD on academic performance. Frequent school absenteeism due to SCD complications, contributed to poor academic performance. He also noted that performance in children with SCD was far below their matched comparison group and below the norms. Children with SCD missed an average of 30 days per year. The reason for absenteeism was mostly due to painful crisis.

Schatz (2004) also examined the impact of SCD on academic achievement. He found that children with SCD had more frequent instances of multiple grade repetitions compared to control group. For children with SCD the mean reading, maths and cognitive ability scores were all lower than those of the comparison group.

In view of the above findings, this study has therefore shown that families and caregivers who are usually mothers of affected children, experience a wide range of psychological problems which leaves them with persistent feelings of helplessness and emotional stress.

5.6 SOCIAL FACTORS

Although providing care for a child with SCD is inherently stressful, other factors such as social support mediate the impact. This statement is supported by Burlew et al (1998) whose research suggested that families who had social support available appeared to cope more favourably with their childs illness. In addition the more social support available to the patient and the family from significant others, the more likely the patient is to comply with the treatment regime.

This study revealed several social implications that are associated with caring for a child affected with SCD. Majority of the respondents 76%(110) expressed that living with a child affected with SCD affects the interrelationship within the home environment among the parents siblings and other immediate family members. The reasons given were that family members did not interact well because the child was often sick and the other siblings cold not even play normally with the affected child due to all health restrictions such as avoiding exhaustion, keeping warm, taking a lot of fluids and many more.

These finding are similar with those of Burlew et al (1998) whose research revealed that the illness challenges the family socially and influences interpersonal relationships within the family. In general the research suggested that the Childs illness has an impact upon the interaction within the family, alters

the parent-child interaction, increased the amount of emotional strain upon the primary caregiver, and threatens social stability of the family.

When the respondents in this study were asked whether having a child with SCD affected their relationship with other people outside the home, majority of them 85%(124) stated that other people stigmatized them, said they were cursed and their child will not grow. It is therefore not surprising that most of the respondents 45%(65)stated that they felt ashamed of other people knowing that they had a child with SCD.

These finding are similar with those of Antle et al (2008) who found that the mothers reported that SCD stigma stemmed from uneducated notion about SCD including beliefs that SCD is a curse placed on certain families because of ancestral wrong doings.

Kofie, Egonjobi & Akinyanju (2009) in a study that sought to explore the psychological impact of SCD in Nigerian population also found similar beliefs. Their study showed that among the Igbo communities SCD is believed to be the result of malevolent 'Ogbanje'(reincarnation) that is repeated cycle of birth, death and reincarnation in cursed families.

Some respondents 21%(31) in this study stated that their relationship with other people outside the home was affected because frequent hospitalization and caring for the child, made socialization with other people difficult. Care giving responsibilities in SCD are challenging and it's mostly the mothers who endure most of the care giving responsibilities

These findings are similar to those of Antle et al (2008) who in their study reported that many mothers had high levels of anxiety about being away from their children for fear that an illness crisis may occur in their absence. This is due to the fact that SCD symptoms can be triggered by many different stimuli (cold or wet temperatures, dehydration, increased heart beat, stress, and lack of rest) and mothers work hard to protect their children from becoming ill. The mothers

ported that they did not make any advance plans of socializing with friends and cked the freedom to feel excited about future social events.

urlew et al (1998) in their study also reported that the presence of child with CD reduces the ability of primary caregiver or parent to participate in social ctivities outside the family.

nterestingly this study has revealed that, majority of respondents 64% (61) eported that their relationship with their spouses was affected due to living with a nild affected with SCD. The respondents reported that their husbands felt eglected because the wives (mothers of affected children) spent most of the me caring for the child. Some of the respondents 5% (10) actually reported that ney had been divorced by their husbands because of having a child with SCD. he wives were blamed to be the ones who caused the disease on the child. This ould be attributed to the fact that as shown from this study, more than half of the espondents had never been jointly counselled (figure 7). Husbands or spouses nay lack Knowledge, awareness and understanding of SCD which leads to them laming their wives.

his study revealed an association between joint spousal counselling regarding CD and relation between spouses being affected due to living with a child with CD (*p* value 0.01 Table 10).

hese findings are similar to those of Brown et al (2010) who found that caring or children with SCD led to disagreement and quarrels in families and brought bout marital disharmony even separation of parents. Causes of marital disability vere multifactorial including severity and frequency of crisis and hospitalizations.

When the respondents in this study were asked whether they had received any orm of support towards the care, majority 63% (91) indicated that they did eceive some support. Out of these, 35% (50) received spiritual support, 23% 33) received material support and 5% (8) received financial support. Most of hose who received spiritual support, got it from the church and those who eceived material support got if from friends whereas financial support came

mostly from family members. Although most of the respondents indicated that they received support, such support was received once in a while and this resulted in the families fending for themselves most of the time. Managing a child with SCD maybe a source of distress therefore a good source of regular and sustained support system for family members helps relieve the burden of care.

However, the study showed that all the respondents whether they received support or not, they all experienced problems when caring for the affected child. (Table 11).This may be attributed to the fact that even though the respondents in this study received some form of support, the support once in a while hence it was not sufficient and effective enough to help relieve the care burden.

5.7 LIMITATIONS OF THE STUDY

The limitations of the study were that, the study was only conducted at UTH and therefore findings cannot be generalized to other areas of the country.

The presence of the interviewer may have hindered the respondents to give detailed information. However, this was taken care of by assuring the respondents of confidentiality, anonymity and also developing good rapport by explaining to them the nature and purpose of the study so as to gain their cooperation and trust.

5.8 IMPLICATIONS OF THE STUDY TO NURSING

5.8.1 Implications to nursing practice

5.8.1.1 Nurses and other health workers have a leading role in the delivery of quality health care in our country. SCD is public health concern in Zambia. Health systems have an important role to play in providing family support and advocacy. With increasing numbers of children with SCD, the health care system and the nursing profession is facing a big challenge .The study revealed that families of patients with SCD face a variety of psychological, social and economical burdens. These are perpetuated by lack of adequate knowledge on the disease, by the families themselves and the community at large, stigma, social isolation,

lack of support and appropriate services. This implies that nurses and other health providers have a challenge of providing adequate IEC, counselling regarding SCD to enable families cope effectively with the illness. Health professionals need to learn more about the manner in which families adapt. This can be achieved through combining medical treatment with assessment of psychological experiences and psychological therapies.

5.8.1.2 Another significant finding from the study is that there is high financial burden on the families caring for children affected with SCD. Frequent hospitalization and illness episodes, demands the family to spend money on health needs of the child leaving the family with economical burdens. Considering the low economical status of majority of the respondents, nurses and health professionals have a challenge of advocating for support services, work in liaison with community, social workers and other stake holders in initiating resource mobilization ventures, fundraising events, and formation of viable SCD association to help assist families in any way possible.

5.8 1.3 The study also revealed that there are inadequate social support services for families and patients with SCD. Paediatric liaison services attending to the social needs of children and families of SCD are limited or virtually nonexistent in Zambia and this complicates the illness and the burden even further. This brings into focus the importance of nurses and health professionals developing liaison services to meet social needs and support to families.

5.8.2 Implications to Nursing Research.

5.8 2.1 Literature review showed that there is limited research done in Zambia regarding issues of SCD. In Zambia SCD is a public health concern. Therefore research on SCD is very important to help come up with appropriate evidence based interventions that can help mitigate the psychological, social and economical problems experienced by patients and families of affected children. Nurses at all levels should be encouraged and supported o conduct research on

SCD. Research is an important component of the programme of SCD management.

5.8.3 Implications to Nursing Education

5.8 3.1 The study revealed that the majority of respondents had low knowledge on SCD mainly due to insufficient avenues of IIEC and not having received counselling on SCD. This is a challenge to all training schools not only for nurses but other health professionals to equip the students with adequate knowledge and skills to enable them conduct IEC sessions as well as counselling of clients and community at large regarding SCD. As shown by this study some of the psychological and social problems stem from inadequate knowledge. SCD has a low profile in Zambia and lacks public awareness and understanding of the disease in general. This is a challenge to educators to stress emphasis on chronic and non communicable disease such as SCD in the same way other disease such as HIV/AIDS, Malaria, and Tuberculosis receive emphasis. This will help in reducing burdens experience by families as well as improve their quality of life.

5.8.4 Implications to nursing Administration and Management

The study revealed that genetic counselling for families with children affected with SCD is inadequate. There is therefore a need for nursing managers in their human resource development plans, to advocate for nurses to undergo genetic counselling skills courses so that they can be able to offer counselling to patients. Together with other team members genetic counselling can be offered to every family that have children affected with SCD in order to equip them with necessary knowledge regarding the disease.

5.9 CONCLUSION

The study sought to assess the problems experienced by immediate family members in caring for children affected with SCD. The findings revealed that knowledge level on SCD among the majority of respondents was low. The low

levels of knowledge were attributed to the fact that most of the respondents had low education level, had not been counselled on SCD and had not received any educational materials regarding SCD. The only single source of information they had was from the health workers. This study revealed significant associations between educational level and knowledge of the disease (*p* value 0.01)

The study findings showed that the families experience psychological problems ranging from depression, guilt feelings, anxiety, and blue moods. There was also a significant association between times the child had been hospitalized in the last six months and depression (*p* value 0.02).

The study also revealed that the families face economical challenges in caring for the children. The economical status of the family was found to be a factor in determining how the family copes financially. A significant association was also found between monthly income and whether the family has ever borrowed money in taking care of family needs due to the presence of a child with SCD in the family (*p* value 0.01).

The study revealed that the families with children affected with SCD did not receive adequate social support and this impacted negatively on the problems they face in caring for the children. Social problems experienced include unfavourable interrelationship within the home environment, problems with spouses including divorce due to presence of child with SCD. The findings of this study revealed a significant association between experiencing problems among spouses with whether the couple has been jointly counselled (*p* value 0.01.) Other social problems experienced by the families include lack of time to socialize with friends outside the home and stigma.

The above findings demonstrate that the financial, psychological and social problems faced by the families of affected children are multifold and are interrelated. Therefore it is important to note that management of children with SCD should not just involve medical treatment but also provision of social,

psychological as well as financial support in order to alleviate the burden caused by caring for a child affected with SCD.

5.10 RECOMMENDATIONS

The following recommendations have been made to the relevant authorities and other stakeholders based on the findings of this study.

1) Ministry of Health should in collaboration with other stake holders and other interested parties introduce National programmes on the care, support and management of SCD patients and their families. These programmes should be incorporated in the policies of management of non communicable diseases and should receive much publicity, awareness and funding that is given to other chronic disease such as HIV/AIDS. This will enable effective and efficient care provision at all levels of health care systems in our country.

2)Health professionals especially doctors and nurses working with children affected with SCD, should spear head to advocate for the formation of Zambia SCD Association which will bring into focus the public health importance of developing liaison services to meet the health, social support, psychological as well as financial support of the patient and the families of affected children. This can be done in collaboration with patients, affected families, social workers, teachers, media ,other interested parties as well as other stake holders. Through the Association important evens such as the World SCD disease day (19 thJune) can be observed in Zambia every year as it is in other countries. SCD is a major public health concern in Zambia and it is high time such an association came into being.

3) There is need to introduce effective and efficient IEC programmes to make the communities in our country aware of SCD. The Ministry of Health and its health workers and stake holders should ensure that there is a variety of avenues of disseminating information such as posters, drama, media both audio and visual, educational videos and many more. This is important to enable SCD have a high public profile and increase public awareness of the disease. This will help better

understanding of the disease in general population and help reduce stigma associated with the disease.

4) SCD is widely distributed in every province of our country, Zambia. Therefore there is need for the Ministry of Health in partnership with interested parties and other stake holders to establish SCD clinics which can be run once or twice a week in every health facility such as district hospitals and major clinics in our communities. These SCD clinics should be run by a multidisciplinary team including paediatricians, nurses, genetic counsellors, and haematologists, physiotherapists to enable proper management and follow up of patients as closer to the community as possible.

5) The service areas such as paediatrics departments in the hospitals, and child health clinics should incorporate into its protocols of management of patients with SCD important aspects such as mandatory counselling sessions on SCD to affected families, and easily understandable literature should be offered to the parents to take home at the end of the session for them to have better understanding of the disease.

6) The Ministry of health in conjunction with other stakeholders such as Ministry of Education should incooperate the aspect of SCD in its school health programmes to help sensitize the pupils, communities, parents as well as the teachers on the disease. This will help increase public awareness of the disease which is a public health concern in our country, Zambia.

7) More studies should be conducted on SCD in Zambia on a large scale because very limited data is available on the disease. Data generated from such research would be useful in formulating appropriate policies and development of programmes aimed at improving the management of children with SCD in Zambia.

5.11 DISSEMINATION AND UTILIZATION OF FINDINGS

A report of the research was written and submitted to the Department of Nursing Sciences of the University of Zambia. Future plans are to submit a final copy to the Medical Library at the School of Medicine and the Ministry of Health.

The study findings were presented at the UNZA Scientific Seminar held on 1 st September 2010 at the UNZA School of Medicine. The seminar was arranged and sponsored by the Directorate of Post Graduate Studies of the UNZA.

An article of the study was also submitted to the Medical Journal of Zambia for publication.

Thereafter the study findings were presented to various stake holders involved in the management of children with SCD. These included the paediatrics department at UTH, so that they could use the study results to render evidence based care as they provide comprehensive management to children with SCD.

REFERENCES

Adeyokunnu,A., & Adeyeri, C. (1999). **Genetic counseling in Sickle cell Disease Ibadan Nigerian experience**. Journal of tropical paediatric Volume 24:148-151

Archbold, P.G. (1983). **Impact of parent –caring on women** .Family relations volume 32: 39-45

Athale, U., & Chintu, C. (1994). **Clinical Analysis of Mortality in Hospitalized Zambian Children with Sickle cell Anaemia.** East African Medical Journal Volume 71:388-391.

Athale, U., & Chintu, C. (1993) .**The effect of Sickle cell Disease on adolescent and growth and development** .Journal of tropical paediatrics.

Atkin, K. & Ahmad, W. (2000). **Living with sickle cell disorder**. Open University Press, Buckingham.

Antle, D., Williams, B., & Cook, C. (2008). **Understanding the experience of raising a child with Sickle Cell Disease**. Health and social work publication.

Ayinmode, T. (2007). **Psychosocial impact of Sickle cell disease on mothers of affected children seen at University of Ilorin Hospital Nigeria.** East African Medical Journal volume 84: 409-410

Basavanthapa, B.T. (1998). **Nursing research.** Jaypee brothers medical publishers Ltd. New Delhi.

Brandow., A. Dousseau, D., & Panepinto, A. (2008). **Post discharge pain functional limitations and impact on caregivers of children with Sickle Cell Disease treated for painful events.** British journal of haematology volume 144: 782-786.

Burlew,A.K. ,Telfair, J., Colangelo.,L. & Wright, E. (2000). **Factors that influence adolescent adaptation to Sickle cell disease** .Journal of paediatric psychology volume 25: 287-299

Burlew ,A.K., Evans, R., & Oler, C.(1998). **Impact of a child with sickle cell disease on family dynamics** .NY academy of science volume 565:161-171

Burns, N. & Grove, S. (2009).**The Practice of Nursing Research.** Sixth edition,

Saunders, St Louis

Day ,S. & Chismark, E. (2000). **The Cognitive and Academic Impact of Sickle Cell Disease**. Journal of Paediatric Psychology volume 22:330-334.

Dempsey ,P.A &Dempsey,A.D.(2000).**Using Nursing Research Process. A critical evaluation and utilization.** Lippincott. Philadelphia.

Enarson ,D., Kennedy, S., Miller, D., & Bakke ,P. (2001). **Research methods: A guide to protocol development for low income countries.** Oxford University Press. New York

Famuyiwa ,O.(1998). **Burden of sickle cell diseases on families of patients.** International journal of social psychiatry volume 44: 170-180.

Fischoff, J. & Jenkins, D. (1987). **Sickle Cell Anaemia in Basic Handbook of Child** Psychiatry. Basic books. New York.

Hamlett ,K.W., Pellignni, D. ,& Karz ,K. (1992).**Childhood chronic Illness as a Family Stressor**. Journal of Paediatric Psychology volume17:33-37

Herron ,S., Bacak, S., King ,A., & Debaum, M.(2003) .**Inadequate Recognition of Education Resources Required for High Risk Students with Sickle Cell Disease** Archives for Pediatrics and Adolescents Medicine volume157 : 104.

Hill ,S.(1994). **Managing Sickle cell Disease in low income families**. Temple University Press, Philadelphia.

Jesuit Center for Theological Reflections. (2000**). Debt and poverty Reduction Growth Facility Report.**

Kanfwa ,V. (1988). **The effect of sickle cell disease on the life of the sickler in the UTH ,Lusaka.**

Kikuchi, B. (2007). **Sickle cell Anaemia, Social Organization and Public Policies**. www.aafesp.org.br

Kliewer, W. & Lewis ,H. (1995). **Family Influence on Coping Process in Children and Adolescents with Sickle cell Disease.** Journal of Paediatric Psychology volume20:511-525

Kuhlthau, K.A. ,& Perrin ,J.M. (2001) .**Child Health and Parental Employment** Archives of Paediatric and Adolescent Medicine, 155: 1346-1350.

Kofie, A. E .,Egonjobi, E., & Akinyanju, O.(2009). **Psychological impact of Sickle Cell Disease in a Nigerian population.** www.globalization and health.com/context.

Moskowitz, J.,Butensky, E., Harmatz, P., Vinchinsky, E., Heyman, M., & Acree, M. (2007). **Care giving Time in Sickle cell Disease: Psychological effects in Maternal Caregivers.** Paediatric Blood Cancer .48:64-71

Mwiinga, M. (2002). **Civil society and the poverty reduction strategy process in Zambia.** Lusaka government printers.

Nettles, A. (1994). **Scholastic performance of children with Sickle Cell Disease** .Journal of health and social policy volume 5:123-140

Ohaeri, J., & Shokunbi,W,.(2002). **Psychosocial burden of sickle cell disesase in Nigeria.** J Natt medical Association volume 9:1058-1070

Olujohungbe, A.O. (2007). **How to Live with Sickle cell Disease**. Book builders. Ibadan.

Oluwole O. (2010). **Awareness of Sickle Cell Disease among youth corpers in Owo, South West Nigeria.** World family medical Journal volume 8.

Okereke ,J,. Lagunyu, I., & Ohawri ,J,. (2010) **Burden of health care of carers of children with sickle cell disease.** Health social care community volume 18: 289-290.

Palermo, T.M., Riley, C., & Mitchel B. (2008). **Daily Functioning and Quality of Life in Children with Sickle cell Diseases: Relationship with Family and Neighborhood Socioeconomic** Distress. Journal of Pain Volume 9; 833-840

Polit, D.F., & Hungler, B.P. (1999).**Nursing Research Principles and Methods**. Sixth edition, Linppincott, Philadelphia.

Royster, M.O, & Shipman, J.R. (1998). **Sickle cell Disease an overview of current services and Emerging needs in the Commonwealth** .http;//www.vahealth .org/sickle cell. Accessed 28 May 2009.

Schatz, J.(2004). **Academic attainment in children with Sickle Cell Disease.** Journal of paediatric psychology volume 29 :627-633.

Shapiro, B., Dinges ,D., Orne, E., & Frempong K. (1995). **Home Management of Sickle cell related Pain in Children and Adolescents and Impact on School Attendance**. Pain journal volume 61: 139-144.

Sickle Cell Disease in the African Region ; Current Situation and the Way Forward .(2006) http;//www.ns/c.Wustl, .edu/sicklecell/prt3/biogeography.html .Accessed 03 April 2009.

Slaughter, D.T, & Anderson, P. (1988).**Care of black children with Sickle cell Disease**. Family Relation Volume 37: 281-287

Stossel ,T. (2006). **Reducing the Misery Burden: A Zambia Based Sickle cell Anaemia Report** .www.Zamsickle .org

Thompson. R.J.. Gilk. K.. & Burbach ,D.(1993). **Psychological Adjustment of Mothers of Children and Adolescents with Sickle cell Disease** .Journal of

Thompson ,J. (1996).**Genetic counselling in Sickle Cell Disease in Ibadan experience** ,Nigeria. Awake magazine

Tripp, R. (1997). **Chronic illness and the Older Adult** .Springer. New York.

Tweel ,V.& Hatzmann ,J. (2008) .**Quality of life of female caregivers of children with Sickle cell Disease**.Haematological journal Volume 93: 588-598

Weatherman ,D,. Fuchareon ,S,.& Olivieri, N,. (2001) .**Disease control priorities in inherited disorders of Hb.** Bulletin of the World health volume 79: 704 -712.

WHO. (2006). **Sickle cell Disease in the African Region current situation and way forward.** www.helpstartshere.org/default.spx (Accessed 12 May 2009.)

www.creresearch.com/sicklecellanaemia/stats-country.htm (accessed 30 May 2011) **Health statistics by country**. US census Bureau International Base 2009.

Sickle cell disease and epidemiology and African American.

www.sicklecelldisease.org/aboutscd/affected (Accessed 5 May 2009)

Youngson, R. (2000). **Health Encyclopedia** .Bloomsbury publishing plc.

APPENDIX i (A)

INFORMATION SHEET

PROBLEMS ENCOUNTERED BY IMMEDIATE FAMILIES IN CARING FOR CHILDREN AFFECTED WITH SICKLE CELL DISEASE.

INTRODUCTION

I, Mercy Mumba Wa Somwe a student of Masters of Science in Nursing at the University of Zambia is kindly requesting your participation in the research study mentioned. It is important to assess the problems encountered by these families so that we can make improvements in care and management of children with SCD and their families.

Before you decide whether or not to participate in this study, I will explain to you the purpose of the study, benefits and what is expected of you. Your participation in this study is entirely voluntary .You are under no obligation to participate, and no privileges will be taken away from you. If you agree to participate you will be asked to sign this consent form in front of someone.

PURPOSE OF THE STUDY

The study will assess the problems encountered by families of children affected with SCD. This is important as the information obtained will help the health care system in our country to take measures in management of children with SCD and alleviate the burdens experienced by the families.

PROCEDURE

After signing the consent form, the interviewer will proceed to ask you the questions and record your response on the questionnaire. This study involves face to face interview with the interviewer who will ask you a set of questions using a structured questionnaire. The interview will take approximately 15 to 20 minutes.

RISKS AND DISCOMFORTS

There is no risk and discomforts involved in this research.

BENEFITS

The information obtained will help improve the management of children with SCD. It will also help policy makers to put up programmes and measures to alleviate burdens experienced by families of affected children, and improve their quality of life.

WITHDRAWAL FROM THE STUDY

You are free to withdrawal from the study at any point during the interview without being obliged to give an explanation. No privileges will be taken from you for refusing to participate.

CONFIDENTIALITY

The information you will give us will be kept confidential. The research records will be kept confidential. Your name will not appear on the questionnaire .The research records will be kept confidential and will only be released to relevant authorities such as Ministry of Health and University of Zambia.

APPENDIX i (B)

MABVUTO YOMWE MA BAJA ALI NDI ANA ODWALA MATENDA A SICKLE CELL APEZANA NAO MUKUSAMALILA ANA AMENEO

CIPEPALA CAUTHENGA WACIDZIWITSO

Ine mai Mercy Mumba Wa Somwe, mwana wa sukulu wa maphuzilo la masitazi mu unasi pa Univesiti la Zambia , ndili wozicepesa kupepha kuti mtengeko mbali ku yakha mafunso la topiki lomwe lachulindwa pamwambapo.Ndichacikulu ndithu kuti tidziwe mabvuto yomwe ma banja yomwe ali ndi ana amatenda a Sickle cell apezana nao, kuti tipeze njila lokometsa katsamalidwe ka ana ameneo ndima banja lao.

Pomwe mukalibe kuvomela kapena kukana kutengako mpata, ndizakufotokozelani mwatsatanetsatane ubwino wache ndizina zace zomwe muyela kudziwa.Kutengako mpata kuyankha mafuso ndikozifunila kwanu nokha osati kokakamidzidwa. Ndipo zibanitso kuti simudza manidwa thandizo iliyonse kapena mankwala cifukwa cakuti mwakana kutengako mpata ai.

Ngati mwavomela kutengako mpata mudzafutsidwa ku saina cipepala pamaso paumboni.

CIFUKWA CACE CAMAFUNSO AMENEO

Mafunso ameneo ndi ofufuzafufuza ma bvuto omwe mabanja ali ndiana amatenda a Sickle cell apezana nao potsamalila ana ameneo. Uthenga umene uzapezeka mumayankho lamafunso ameneo, udzathandizila cigawo ca umi muno mudziko lathu kuti apeze njila zokoma zoyetsetse kupepusako mubvuto yomwe ma baja ameneo apezana nao.

ZOMWE ZIZICITIKA

Pomwe mtavomela kutengako mbali kuyankha mafunsoameneo,mudzapatsidwa

cipepala cosaina kusonyedza kuti indedi mwavomela. Pambuyo pace Mzankhala ndimuthu omwe azayamba kumufutsani mafunso ameneo

pamatsondipamatso kucokela pacipepala pomwe mafunso ameneo ndiyolebedwa kale. Ndipo munthu ameneyo adza lemba mayankho anu pacipepela pomwepo.Kufutsamafutso ameneo kudzatenga thawi yokwana ngati pakati pa 15-20 maminetsi.

ZOIPA ZACE ZOTENGAKO MBALI

Koma kulibe zoipa zilizonse zomwe zingapezeke kumuthu aliyense yemwe kamba kovomela kutengako mbali kuyankha mafunso ameneo.

UBWINO WACE WOYANKHA MAFUNSO AMENEO

Uthenga umene uzapezeka mumayankho lamafunso ameneo uzathandizila kukomesa katsamalilidwe ka ana ali ndimatenda a Sickle cell, ndikutitso athu acikulilecikulile omwe apanga malamulo mudziko lathu, apeze njila yopepukitsako mabvuto yomwe ma banja ali ndiana amatenda a Sickle cell apezana nao.

ZACISINSI

Uthenga omwe uzapasidwa poyankha mafunso, uzasungidwa mwacisinsi ndithu.Dzina lanu silizasonyezendwa pamapepala ameneo.Mapepala ameneo azaonesedwa cabe ku athu ukhuzindwa, acigawo ca umi mziko lathu ndi a univesiti la Zambia kwatha.

APPENDIX ii (A)

INFORMED CONSENT FORM

The purpose of this study has been explained to me and I understand the purpose, benefits and confidentiality of the study. I further understand that if I agree to take part in this study, i can withdraw at any time without having to give explanation and that I will not be denied treatment. Taking part in this study is purely voluntary.

I ----------

(Names)

Agree to take part in this study.

Signed: ---------- Date: ----------

(Participants signature or thumb print)

Signed (witness) ---------- Date: ----------

Signed (Researcher) ---------- Date: ----------

PERSONS TO CONTACT FOR PROBLEMS OR QUESTIONS

1.Mercy Mumba Wa Somwe, University of Zambia, Department of Nursing Sciences, P.O Box 50110, Lusaka.
Tel 0977258268

2.Mrs. C, Ngoma, University of Zambia, Head of Department Nursing Sciences, P.O Box 50110, Lusaka.
Tel 0211 252454

3.The Chairperson, Research Ethics Committee, University of Zambia, P.O Box 50110, Ridgeway Campus, Lusaka.
Tel 0211 256067

APPENDIX ii (B)

CIDZIWITSO NDICIPEPALA COSAINA

Cifukwa cace camafunso ameneo cafotokozedwa ndipo ndamva ubwino wace ndicisinsi cace .Ndipo ndamvesaso kuti nditavomela kutengako mbali kuyankha mafunso ameneo, ndingalekenso nthawi iliyonse kutengako mbali kopanda kupasa fotokozo yomwe ndalekela kutengako mbali. Kutengako mbali kuyankha mafunso ameneo sikokakamizidwa, koma ndikozifunila munthu paekha.

Ine ----------

Ndavomela kutengako mbali

Kusaina----------(Wotengako mbali) Tsiku lalelo----------

(Chisaino camunthu wotengako mbali kapena cidindo cazanja lake)

Kusaina---------- (Wa umboni) Tsiku lalelo----------

Kusaina ----------(Mwine wace wamafunso amenewo) Tsiku lalelo----

ANTHU OGWILIZANA NAO NGATI MUFUNA KUDZIWA DZINA ZACE

1.Amai Mercy Mumba Wa Somwe ,Univesiti la Zambia,Cingawo ca maphuzilo ya manasi, PO Box 50110, Lusaka. Foni lao: 0977258268

2.Amai C . Ngoma , Akulu oyanganila mamphnzilo yanasi, Univesiti la Zambia PO Box 50110,Lusaka.

Foni lao :0211 252453

3. Akulu akumpando la komiti loyanganila cingawo camaphuzilo Univesiti la Zambia, PO Box 50110, Lusaka.

Foni lao: 0211 256067

APPENDIX iii BUDGET

BUDGET CATEGORY	UNIT COST (ZMK)	QUANTITY	TOTAL (ZMK)
STATIONERY			
1.Bond paper	30,000.00	10 reams	300,000.00
1. Pens	1,000.00	10	10,000.00
2. Pencils	1,000.00	10	10,000.00
3. Rubbers	1,000.00	10	10,000,00
4. Note books	10,000.00	5	50,000.00
5. Correction fluid	15,000.00	2bottles	30,000.00
6. Stapler	30,000.00	2	60,000.00
7. Bags	100,000.00	3	300,000.00
8. Scientific calculator	100,000.00	1	100,000,00
9. Printer toner	1,000000,00	1	1,000000.00
10. Flash disc	200,000.00	2	400,000.00
11. Laptop	1,000000,00	1	1,000000.00
12. printer	1,000000.00	1	1,000000.00
SUBTOTAL			**3,270,000.00**
PERSONNEL			
1. Lunch allowance Research assistance	50,000.00	3x10 days	1,500,000.00
2. Lunch allowance Researcher	50,000.00	1x 10 days	500,000.00
3. Transport Research assistance	50,000.00	3x 10 days	1,500,000.00
4. Transport Researcher	50,000.00	1 x 10 days	500,000.00
SUBTOTAL			**4,000,000.00**

SERVICES			
1. Ethics committee	250,000.00	1	250,000.00
2. Photocopy proposal	30,000.00	10 x 50 p	150,000.00
3. Photocopy questionnaire	30,000.00	145x10p	300,000.00
4. Proposal and report	60,000.00	3	120,000.00
5. Translating consent and questionnaire	200,000.00	1	200,00.00
6. Software packages	100,000.00	2	200,000.00
7. Data entry	1,000,000.00	1	1,000,000.00
8. Data analysis	300,000.00	1	300,000,00
9. Photocopy report	30,000.00	5x200p	150,000.00
10. Binding	40,000.00	5	200,000.00
11. Research proposal	250,000.00	5	1,250,000.00
12. Research reports	250,000.00	5	1,250,000.00
SUBTOTAL			**6,370,000.00**
SNACKS FOR PARTICIPANTS			
1. Biscuits	3,000.00	290 pkts	870,000.00
2. Drinks	2,000.00	290 bottles	580,000.00
SUBTOTAL			**1,450,000.00**
TOTAL			**15,090,000.00**
CONTIGENCY 10%			**1,509,000.00**
GRAND TOTAL			**16,599,000.00**

JUSTIFICATION FOR THE BUDGET

STATIONERY

The reams of paper will be used for the research proposal development, extra copies for proposal submission for graduate forum, Ethics committee and the final report. The same paper will be used for the interview schedule.

The flash disc is necessary for storage and safe keeping of research data.

All other accessories such as pens, pencils, staples, note books and others are all required during the entire process of the study.

PERSONNEL

The researcher will involve 2 research assistants to help in data collection. These will need to be trained in the use of the questionnaire in the data collection process, given transport money to travel to the research site, lunch allowance for the whole of data collection period as well as have bags for carrying necessary logistics.

TYPING SERVICES

Funds for typing, photocopying, printing, binding of research proposals for post graduate forum, Ethics committee, questionnaires, reports, analysis and dissemination will be needed.

CONTIGENCY

Contingency fund which is 10% of the budget is required for any extra costs due to inflation and any eventualities.

APPENDIX iV GANTT CHART

APPENDIX V (A)

TO BE RMED	RESPONSIBLE PERSON	Jun	Jul	Aug	sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun
re	Researcher													
al pment	Researcher													
tation duate s	Researcher													
val by	REC													
tion	Researcher and research assistance													
sis	Researcher													
t g	Researcher													
ission aft rt	Researcher													
nission al rt	Researcher													
emination sults	Researcher													

SEMI STRUCTURED INTERVIEW SCHEDULE FOR PARENTS AND GUADIANS

THE UNIVERSITY OF ZAMBIA

SCHOOL OF MEDICINE, DEPARTMENT OF NURSING SCIENCES.

PROBLEMS ENCOUNTERED BY IMMEDIATE FAMILIES IN CARING FOR CHILDREN AFFECTED WITH SICKLE CELL DISEASE, SEEN AT UTH PEDIATRICS DEPARTMENT, LUSAKA.

CODE NUMBER : ----------

DATE OF INTERVIEW: ----------

PLACE OF INTERVIEW: ----------

NAME OF INTERVIEWER: ----------

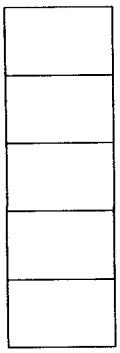
INSTRUCTIONS FOR THE INTERVIEWER

1. Introduce yourself.
2. Explain the reasons for the interview.
3. Do not write names of respondents on the interview schedule.
4. Tick in the box the appropriate response to the question or fill the answer in the space provided.
5. Assure respondents confidentiality, privacy and anonymity at all times during the interview schedule.
6. Provide time for the respondent to ask questions at the end of the interview.
7. Thank the respondents at the end of the interview.

SECTION A DEMOGRAPHIC DATA

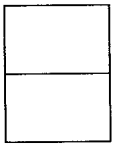
1. Age at last birthday

2. 15-24 years
3. 25-34 years
4. 35-44years
5. 45 years and above



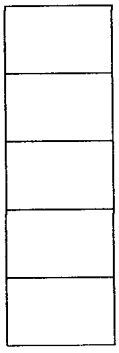
2.Sex

1.Male
2.female



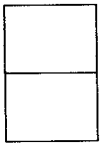
3. Marital status

1. single
2. Married
3. Divorced
4.Separate
5. Widowed



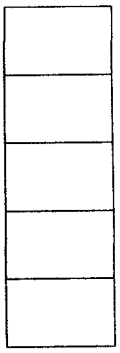
4. Number of children

1. 1-4
2. 5 and above



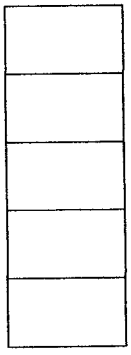
5. Highest level of education attained

1. None
2. Primary
3. Secondary
4. College
5. University



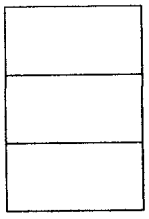
6. Occupation

1. Housewife
2. Student
3. Formal employment
4. Self employed
5. Unemployed



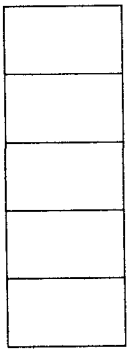
7. Monthly income of the family

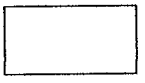
1. Above K 1,000,000
2. Between K 1,000,000- K5000
3. Below K 500.000



8. Relationship to the child

1. Mother
2. Father
3. Sister
4. Brother
5. Other (specify)





9. Age of child at last birthday

1. below 1 year
2. 1-3 years
3. 4-5 years
4. 7-9 years
5. 10 years and above

10. Educational level of child

1. None
2. Pre school
3. Grade 1-4
4. Grade 5-8
5. Grade 9-12

SECTION B KNOWLEDGE ON SCD

11. What is Sickle cell Disease?

_____

_____

_____

12. What causes Sickle cell Disease?

_____

13. In your opinion do you think that Sickle cell Disease can be cured?

1. Yes
2. No

14. If your answer to question 13 is yes, how can it be cured?

_____ ☐

15. Do you think that Sickle cell Disease can be prevented?

1. Yes
2. No

☐ ☐ ☐

16. If the answer to question 15 is yes, explain

_____

_____

_____ ☐

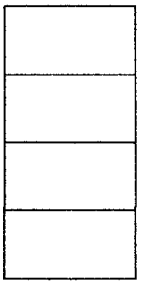
17 .Indicate whether you have ever received any of these informational materials on Sickle Cell Disease

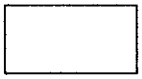
1. Posters
2. Books
3. Pamphlets
4. Video tape
5. None
6. Other specify

☐ ☐ ☐ ☐ ☐ ☐

18. What is your usual source of information regarding Sickle cell Disease issues?

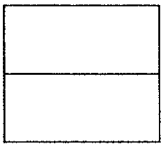
1. Health professional
2. Media
3. Relatives
4. Friends
5. Other (specify)

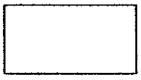




19. Have you ever been counseled jointly with your spouse regarding Sickle cell Disease?

1. Yes
1. No

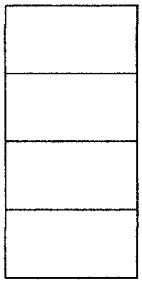




SECTION C ECONOMICAL FACTORS

20. How much do you usually spend when child is hospitalized?

1. K500.000 and above
2. Between K500.000- K400.000
3. K300.000-200.000
4. K 100.000 and below



21. What usually do you spend the money on?
    1. Transport
    2. Medicines
    3. Food
    4. Investigations
    5. Other (specify)

22. Explain whether any member of your family been unable to work due to caring for the child

_____

_____

_____

23. Have you ever borrowed money to take care of your family needs due to the presence of a child with Sickle cell Disease?

    1 .Yes
    2. No

24. In your own opinion do you feel that the presence of a child with Sickle cell Disease affects your families' financial status?

    1. Yes
    2. No

25.If the answer to question 24 is yes, explain

_____

_____

_____

SECTION D PSYCHOLOGICAL FACTORS

26. Does living with a child affected with Sickle cell Disease make any of your family member(s) feel depressed?
    1. Yes
    2. No

27 .If the answer to question 26 is yes, explain _____

28. Does living with a child affected with Sickle cell Disease, make any family member (s) feel guilty?

    1. Yes
    2. No

29. If the answer to question 28 is yes, explain

_____

30. How often do you have negative feelings such as blue moods, anxiety?

1. Never
2. Quite often
3. Always

31. Give reasons for answer to question 30 _____

_____

_____

32. How many time has the child been hospitalized in the last 6 months

1. More than 6 times
2. 4-5 times
3. Less than 4 times

33. Explain if Childs schooling is affected due to his illness

_____

_____

_____

SECTION E SOCIAL FACTORS

34. Does living with a child affected with sickle cell disease affect the interrelationship within the home environment?

1.Yes
2. No

35. If the answer to question 34 is yes, explain

_____

_____

36. Does having a child affected with Sickle cell Disease affect the relationship of your family members with other people outside your home?

1.Yes
2.No

37. If the answer to question 36 if yes, explain

_____

_____

38. Does having a child with Sickle Cell disease affect your relationship with your spouse?

1.Yes

2.No

39. If the answer to question 38 is yes , explain

_____

_____

40. Indicate any form of support you receive towards the care of your child

1. Financial
2. Material
3. Spiritual
4. Any other specify

41. Who provides the support?

1. Family members
2. Other relatives
3. Friends
4. Church
5 Other (specify)

42. How often do you receive this support?

1. Once in a while
2. Very often
3. Always

43. Explain whether your family members feel ashamed of others knowing your child has Sickle cell Disease

_____

_____ ☐

_____

44. In your own opinion do you think families experience any problems in caring for the children affected with Sickle Cell Disease?

1. Yes ☐
2. No ☐

☐

45 In your own opinion what do you think should be done to help improve the care of children affected with Sickle cell Disease by families?

_____

_____

☐

END OF INTERVIEW

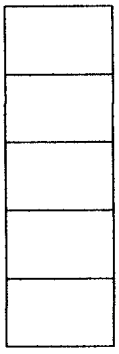
THANK YOU FOR YOUR PARTICIPATION

APPENDIX V (B)

CHINGAWO COYAMBA

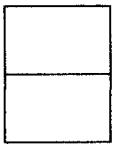
1.Zaka zanu zobadwa

1.15-20 myaka
2 .21-26 myaka
3 .27-32 myaka
4.33-38 myaka
5. 39 ndikupyolela



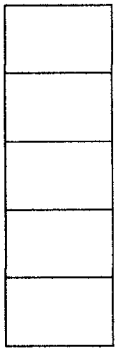
2. Kondi ndinu

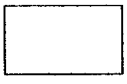
1. Mwamuna
2. Mkazi



3. Kodi ndinu

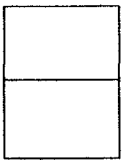
1.Wosakwatila
2. Wokwatila
3. Wosiyindwa mucikwati
4.Wopatukana mucikwati
5. Wofedwa





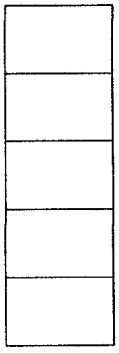
4. mulindi ana angati?

1. 1 -4
2. 5 ndikupyolela



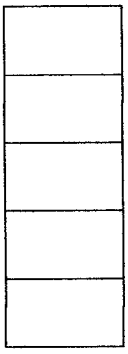
Pamene munafikila maphunzilo

1. Wosapitako ku sukulu
2. Pulaimale
3. Sekondale
4. Kukoleji
5. Ku univeziti



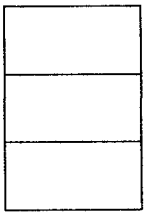
Mungwila ncito bwanji?

1. Mzimai wapa nyumba
2. Mwana wasikulu
3. .Ncito yolebendwa
4. .Ncito yozilemba
5. Paulova



Ndalama ya pamwezi ya banja

1. Ipyolela K 1,000,000
2. Pakatipa K 1,000,000-
   K 500,000
3. Pansi pa K500,000



8. Ubale wanu ndimwanayu

1. Mai wace
2. Tate wace
3. Mulongosi wace wacikazi
4. Mulongosi wace wacimuna
5. Wina wace----------

9. Ali ndizaka zingati mwanayu
   1. Sanakwanitse caka cimodzi
   2. Zaka 1-3
   3. Zaka 4-5
   4. Zaka 7-9
   5. Zaka10 ndikupyolelapo

10. Maphunzilo amwanayu
    1. Saphunzila
    2. Sikulu ya ana ang'ono
    3. Geledi 1-4
    4. Geledi 5-8
    5. Geledi 9-12

CHINGAWO CA CHIWIRI

11. Kodi Sickle cell ndi matenda abwanji?

_____

_____

_____

12. Kodi matenda a Sickle cell abwela bwanji?

_____

13. Mukudziwa kwanu kodi matenda a Sickle cell anga cilizidwe?
    1. Inde
    2. Iyai

14. Ngati lakho lanu kufunso 13 ndi inde, fotokozani

_____

_____

_____

15. Kodi matenda a Sickle cell anga cingilizidwe?
    1. Inde
    2. Iyai

16. Ngati lakho lanu kufunso 15 ndi inde, fotokozani mocingilizila matenda a Sickle cell

_____

_____

_____

17 .Kodi munalandilapo maphunzilo pa matenda a Sickle cell kucokela

1. Zithunzithunzi
2. Mumabuku
3. Tumapepala
4. Muzikope za kanema
5. Kulibe
6. Zina zace

18. Kodi thawi zones uthenga wamapthunzilo pa matenda a Sickle cell muulandila kucoka kwayani?
    1. Ancito aku cipatala
    2. Pamwela
    3. kwa acibale
    4. Kwabwenzi
    5. Ena ace----------

19. kodi munalandlapo uthenga wa tethezo pa matenda a Sickle cell inu ndi amuna anu?

    1.inde
    2.iyayi

CHIGAWO CACITATU

20. Kodi Mumataya ndalama zingati nthawi imene mwanayu ngati alimu cipatala?

1. kupyolela K500.000
2 Pakatipa K500.000- K400.000
3. Pakatipa K300.000- K200.000
4. Pansi pa K 100.000

21. Kodi mumazisebenzesa kuciani ndalama zimenezi?

1. Kumayendedwe
2. Kumankwala
3. Kuzakudya
4. Kuzofufuza fufuza pamatenda

5. Zina zace _____

22. Fotokozani ngati kundankhalapo nthawi imene mmodzi pabaja alephela kupita kuncito kamba kosamalila mwanayu wamatenda a Sickle cell

_____

_____

23. Kodi kulipo nthawi imene mundakongola ndalama zosamalila banja lanu cifukwa cokhala ndimwana wodwala matenda a Sickle cell?

1 .Inde
2. Iyai

24. Mumaganizo anu ,kodi kukhala ndimwana wodwala matenda a Sickle cell kumasokoneza mkhalidwe wandalama zapa banja lanu ?

1. Inde
1. Iyai

25.Ngati lankho lanu kufunso 24 ndi inde, fotokozani

_____

_____

CHIGAWO CACINAI

26. Kodi anthu apabanja lanu amakhala okhumudwa cifukwa cokhala ndimwana wa matenda a Sickle cell pabanja?

1. Inde
2. Iyai

27 . Ngati lakho lanu kufunso 26 ndi inde ,fotokozani

_____

_____

28. Kodi kukhala ndimwana wamatenda a Sickle cell pabaja kumalengeza athu apabaja kukhala amanyazi?

1. Inde
2.Iyai

29. Ngati lankho lanu kufunso 27 ndi inde ,fotokozani

_____

30.Ndikangati pomwe mumakhala ndimaganizo yokhumudwa monga kusasangalala?

1.kulibe
2.Kabilikabili
3.Nthawi zonse

31. Fotokozani zifukwa zalankho lanu kufunso 30

_____

32. Kodi mwanayu anakhalapo kangati mucipatala pa myezi isanu ndi imodzi yapitapo?

1. Kupyolela 6
2. Pakatika 4-5
3. Sinakwane 4

33. Fotokozani kodi mwanayu amapeza mabvuto otani ku sukulu cifukwa camatenda a Sickle Cell

_____

_____

CIGAWO CACISANU

34.Fotokozani mwatsatane ngati kukhala ndimwana wa matenda a Sickle cell kukhuza ubale pakati kamakolo, ana, kapena ena ace pa khomo lanu .

_____

35. ngati lankho lanu kufunso 3 ndi inde fotokozani

---

36. kondi kukhala ndimwana wa matenda a Sickle cell kukhuza ubwenzi wa anthu apabanja lanu ndi athu ena akunja kwa banja lanu

1. inde
2. iyai

37. ngati lakho lanu kufunso 36 ndi inde , fotokozani

---

38. kodi kukhala ndimwana wa matenda a Sickle cell kudzesa msokonezo pakati ka amai ndi abambo apakhomo?

1. inde
2.iyai

39. ngati lankho lanu kufunso 38 ndi inde fotokozani mwatsatane

---

40.. Chulani njila iliyonse yathadizo imene mumalandila posamalila mwanayu

1. Ndalama
2. Katundu
3. Mapemphelo
4.Ina yace

APPENDIX VI

MARKING KEY FOR INTERVIEW SCHEDULE

SECTION B KNOWLEDGE ON SICKLE CELL DISEASE			
QUESTION NUMBER	QUESTION	ANSWER	MAXIMUM SCORES
12	What is SCD?	SCD is a chronic incurable genetic disorder passed on from parents to their off springs	3
13	What causes SCD?	SCD is caused by parents passing on the abnormal genes that causes the abnormal Hb in the blood	3
14	In your opinion do you think that SCD can be cured?	1.yes 2.No	2
15	Do you think that SCD can be prevented?	1.Yes 2.No	2 1
16	If the answer to question 15 is yes explain	SCD can be prevented by couples going for genetic counselling so that they do not continue having children born with the abnormal gene	3
17	Indicate whether you have received any of these informational materials	1 posters 2 Pamphlets 3 Books 4 Video tape	1 1 1 1
18	What is your usual source of information regarding SCD issues?	1 Health professional 2 Media 3 Relatives 4 Friends	2 2 1 1

MARKING KEY FOR INTERVIEW SCHEDULE CONTINUED'

SECTIO N C : ECONOMICAL FACTORS			
20	How much do you spend when child is admitted in hospital	1.K 500.00 and above 2. Between k500.000 to K 400.000 3.K 300,000 to k 200,000 4. K 100,000 and below	1 2 3 4
21	What do you usually spend the money on?	1.Transport 2.Medication 3.Food 4.Investigations	1 1 1 1
23	Have you ever borrowed money to take care of family needs?	1.Yes 2.No	1 2
24	In your own opinion do you think families of a child affected with SCD affects families financial status?	1.Yes 2.No	1 2
SECTION D PSYCHOLOGICAL PROBLEMS			
26	Does living with a child affected with SCD make family members depressed?	1.Yes 2.No	1 2
28	Does living with a child affected with SCD make any family member feel guilt?	1.Yes 2.No	1 2
30	How often do you have negative feelings such as blue moods, anxiety	1.Never 2.Quite often 3.Always	1 2 3
32	How many times has the child been admitted in the past six months	1.More than six times 2.4-5 times 3.Less than 4 times	1 2 3
SECTION E SOCIAL FACTORS			
34	Does living with a child affected with SCD affect interrelationship in the home	1.Yes 2.No	1 2
36	Does living with a child affected with SCD affect relationship with other people outside home	1.Yes 2.No	1 2
38	Does having a child affected with SCD affect relationship with spouse?	1.Yes 2.No	1 2
40	What form of support do you receive?	1.Fnancial 2.Material 3.Spiritual	1 2 3

THE UNIVERSITY OF ZAMBIA
SCHOOL OF MEDICINE

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Telegram: UNZA, Lusaka
Telex: UNZALU ZA 44370
Email: kbowa@yahoo.com

P.O. Box 50110
Lusaka, Zambia

==========

29th October, 2009

Mrs Mercy M. Wasomwe
Department of Nursing Sciences
LUSAKA

Dear Mrs Wasomwe,

RE: GRADUATES PROPOSAL PRESENTATION FORUM (GPPF)

Having assessed your dissertation entitled **"A Study to Assess Problems Encountered by Families of Children Affected with Sickle Cell Disease. University Teaching Hospital, Lusaka".** We are satisfied that all the corrections to your research proposal have been done. The proposal meets the standard as laid down by the Board of Graduate Studies.

You can proceed and present to the Research Ethics.

Yours faithfully,

Mr. K. Bowa, MSc, M.Med, FRCS, FACS, FCS (Urol)
ASSISTANT DEAN, POSTGRADUATE

CC: Head of Department – Nursing Sciences

THE UNIVERSITY OF ZAMBIA

BIOMEDICAL RESEARCH ETHICS COMMITTEE

Telephone: 260-1-256067
Telegrams: UNZA, LUSAKA
Telex: UNZALU ZA 44370
Fax: + 260-1-250753
E-mail: unzarec@unza.zm

Ridgeway Campus
P.O. Box 50110
Lusaka, Zambia

Assurance No. FWA00000338
IRB00001131 of IORG0000774

10 March, 2010
Ref.: 007-12-09

Mr Mercy M. Wa Somwe
Department of Nursing Sciences
School of Medicine, University of Zambia
LUSAKA

Dear Mrs Wa Somwe,

RE: SUBMITTED RESEARCH PROPOSAL: **"A STUDY TO DETERMINE PROBLEMS ENCOUNTERED BY IMMEDIATE FAMILY MEMBERS IN CARING FOR CHILDREN AFFECTED WITH SICKLE CELL DISEASE, UNIVERSITY TEACHING HOSPITAL, LUSAKA"**

The above-mentioned research proposal was presented to the Biomedical Research Ethics Committee meeting on 16 December, 2009 where changes/clarifications were recommended. We would like to acknowledge receipt of the corrected version with clarifications. The proposal is now approved.

CONDITIONS:

- This approval is based strictly on your submitted proposal. Should there be need for you to modify or change the study design or methodology, you will need to seek clearance from the Research Ethics Committee.
- If you have need for further clarification please consult this office. Please note that it is mandatory that you submit a detailed progress report of your study to this Committee every six months and a final copy of your report at the end of the study.
- Any serious adverse events must be reported at once to this Committee.
- Please note that when your approval expires you may need to request for renewal. The request should be accompanied by a Progress Report (Progress Report Forms can be obtained from the Secretariat).
- Ensure that a report on the findings is submitted to this Committee.
- **Ensure that you submit the final report of the study to this Committee**

Yours sincerely,

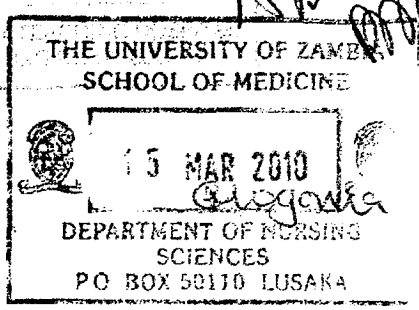
Dr James Munthali
A/CHAIRPERSON
Date of approval: 10 March, 2010 **Date of expiry:** 9 March, 2011

The University of Zambia
School of Medicine
Department of Nursing Sciences
P.o Box 50110
LUSAKA

15th March 2010

The Managing Director
University Teaching Hospital
LUSAKA

u.f.s Head of Department
University of Zambia
Department of Nursing Science
LUSAKA



Dear Sir,

RE: PERMISSION TO CONDUCT RESEARCH STUDY

I am a Masters of Science in Nursing student at the University of Zambia currently pursuing the second and final part of the programme.
In partial fulfillment of this programme, I am required to conduct a Research Study. The topic of my study is "***To assess the problems encountered by immediate family members in caring for children affected with Sickle Cell Disease, at University Teaching Hospital, Lusaka.***"
Data for the study will be collected from parents /Guardians attending the Sickle Cell Disease clinic .Collection of data is anticipated to take place in the months of March and April 2010.
I am therefore seeking permission to conduct the research study at your institution.
Find attached a copy of letter of clearance from University of Zambia Research Ethics Committee.
I would be very grateful if my request met your outmost favourable consideration.

Yours sincerely
Mercy Mumba Wa- Somwe
(Masters of Science in Nursing Student)

THE UNIVERSITY OF ZAMBIA
SCHOOL OF MEDICINE

Department of Paediatrics and Child Health

Telephone: 254965
252641 (UTH) 254824 *(Pre-Clinical) Ridgeway* Campus

P.O Box 50110
LUSAKA, Zambia

16th March, 2010

Mrs Mercy Mumba Wa Somwe
Dept. of Nursing Sciences
School of Medicine
University of Zambia
P. O. Box 50110
LUSAKA

Dear Madam,

RE: PERMISSION TO CONDUCT RESEARCH AT THE SICKLE CELL DISEASE CLINIC

I am pleased to inform you that permission has been granted by the Senior Medical Superintendent for you to carry out the above-motioned study at the University Teaching Hospital.

This is indeed an important study as it will help us understand problems encountered by families caring for children suffering from sickle cell anaemia.

Best wishes.

Dr. S. Wa Somwe
HEAD OF DEPARTMENT

c.c. Dr. V. Mulenga, Clinical HoD
Dr. P. Sambo, Head of Haemato-oncology Unit
The Sister In-charge, Clinic 4
The Clerk, Clinic 4