KNOWLEDGE AND PRACTICES OF PARENTS AND CARETAKERS TOWARDS PREVENTION OF SICKLE CELL CRISES IN CHILDREN WITH SICKLE CELL DISEASE AT THE UNIVERSITY TEACHING HOSPITAL (LUSAKA)

BY

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THE UNIVERSITY OF ZAMBIA

SCHOOL OF MEDICINE

DEPARTMENT OF NURSING SCIENCES

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TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>PAGE No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acknowledgement</td>
<td>i</td>
</tr>
<tr>
<td>Table of contents</td>
<td>ii</td>
</tr>
<tr>
<td>List of tables</td>
<td>vii</td>
</tr>
<tr>
<td>List of figures</td>
<td>viii</td>
</tr>
<tr>
<td>List of appendices</td>
<td>ix</td>
</tr>
<tr>
<td>List of abbreviations</td>
<td>x</td>
</tr>
<tr>
<td>Declaration</td>
<td>xi</td>
</tr>
<tr>
<td>Statement</td>
<td>xii</td>
</tr>
<tr>
<td>Dedication</td>
<td>xiii</td>
</tr>
<tr>
<td>Abstract</td>
<td>xiv</td>
</tr>
</tbody>
</table>

CHAPTER 1

1.0 Introduction .......................................... 1
1.1 Background ............................................. 1
1.2 Statement of the problem ......................... 4
1.3 Analysis of factors influencing knowledge and practices .................. 6
1.3.1 Service related factors .......................... 6
1.3.2 Socio-economic and cultural factors .............. 7
1.3.3 Social-cultural factors .......................... 8
1.4 Problem analysis diagram................................................................. 10
1.5 Theoretical frame work................................................................. 11
1.6 Justification.................................................................................... 15
1.7 Research objectives......................................................................... 15
1.7.1 General objective......................................................................... 15
1.7.2 Specific objectives....................................................................... 15
1.8 Hypothesis...................................................................................... 16
1.9 Conceptual definition of terms....................................................... 16
1.10 Variables....................................................................................... 17

CHAPTER 2

2.0 Literature review........................................................................... 20
2.1 Knowledge on prevention of sickle cell crises............................... 21
2.2 Practices of preventive measures................................................... 24
2.3 Information, Education and Communication................................. 26
2.4 Economic status of a family............................................................. 27
2.5 Conclusion...................................................................................... 28
CHAPTER 3

3.0 Research methodology................................................................. 29
3.1 Research design................................................................. 29
3.2 Research setting................................................................. 30
3.3 Study population................................................................. 30
3.4 Sample selection................................................................. 30
3.5 Sample size................................................................. 31
3.6 Operational definition of terms................................................. 31
3.7 Data collection tool................................................................. 32
3.7.1 Interview schedule......................................................... 33
3.7.2 Validity................................................................. 33
3.7.3 Reliability................................................................. 34
3.8 Data collection technique..................................................... 34
3.9 Pilot study................................................................. 35
3.10 Ethical and cultural consideration........................................... 36
# CHAPTER 4

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.0 Data analysis and presentation of findings</td>
<td>37</td>
</tr>
<tr>
<td>4.1 Data analysis</td>
<td>37</td>
</tr>
<tr>
<td>4.2 Presentation of findings</td>
<td>37</td>
</tr>
<tr>
<td>4.2.1 Demographic data</td>
<td>38</td>
</tr>
<tr>
<td>4.2.2 Socio-economic data</td>
<td>40</td>
</tr>
<tr>
<td>4.2.2 Knowledge on prevention of Sickle Cell Crises</td>
<td>41</td>
</tr>
<tr>
<td>4.2.3 Practices on prevention of Sickle Cell Crises</td>
<td>47</td>
</tr>
<tr>
<td>4.2.4 Social and cultural beliefs/practices</td>
<td>51</td>
</tr>
</tbody>
</table>

# CHAPTER 5

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.0 Discussion of findings and implications for health care system</td>
<td>55</td>
</tr>
<tr>
<td>5.1 Characteristics of the sample</td>
<td>55</td>
</tr>
<tr>
<td>5.2 Discussion of each Variable</td>
<td>56</td>
</tr>
<tr>
<td>5.2.1 Knowledge on prevention of Sickle Cell Crises</td>
<td>56</td>
</tr>
<tr>
<td>5.2.2 Practices on prevention of Sickle Cell Crises</td>
<td>58</td>
</tr>
<tr>
<td>5.2.3 Economic status</td>
<td>59</td>
</tr>
<tr>
<td>5.2.4 IEC on prevention of Sickle Cell Crises</td>
<td>60</td>
</tr>
<tr>
<td>5.2.5 Socio-cultural beliefs/practices on prevention of SCC</td>
<td>61</td>
</tr>
</tbody>
</table>
5.3 Significance to Nursing................................................................. 63
5.3.1 Nursing practice................................................................. 63
5.3.2 Nursing education............................................................... 63
5.3.3 Nursing administration....................................................... 63
5.3.4 Nursing research................................................................. 64
5.4 Conclusion.............................................................................. 64
5.5 Recommendation................................................................. 65
5.6 Dissemination of findings....................................................... 66
5.7 Limitations of the study......................................................... 66
5.8 References............................................................................. 68
LIST OF TABLES

Table number

Table 1: Variables and cut off points.................................................. 18
Table 4.1: Age distribution................................................................. 38
Table 4.2: Marital status................................................................. 38
Table 4.3: Number of children.......................................................... 39
Table 4.4: Number of children with Sickle Cell Disease...................... 39
Table 4.5: Level of education.......................................................... 40
Table 4.6: Occupation...................................................................... 40
Table 4.7: Family income per month............................................... 41
Table 4.8: Predisposing factors of Sickle Cell Crises......................... 42
Table 4.9: Known preventive measures of Sickle Cell Crises.............. 43
Table 4.10: Adequacy of information ............................................. 44
Table 4.11: Age in relation to Knowledge.......................................... 46
Table 4.12: Level of education in relation to knowledge.................... 46
Table 4.13: Adequacy of information in relation to knowledge............ 47
Table 4.14: Home prevention of Sickle Cell Crises............................ 47
Table 4.15: Methods of preventing Sickle Cell Crises....................... 48
Table 4.16: Level of practices on prevention of Sickle Cell Crises........ 48
Table 4.17: Age in relation to practices.......................................... 49
Table 4.18: Level of education in relation to practices ................................................. 49
Table 4.19: Family income per month in relation to practices ................................. 50
Table 4.20: Adequacy of information in relation to practices ................................. 50
Table 4.21: Awareness of any negative social and cultural beliefs/practices ............... 51
Table 4.22: Known cultural beliefs/practices towards prevention of SCC ............... 51
Table 4.23: Ever practiced any cultural methods of prevention of SCC ................. 52
Table 4.24: Practice of cultural methods of preventing SCC in relation to level of Knowledge towards prevention ................................................................. 52
Table 4.25: Practice of cultural methods of preventing SCC in relation to level of Practices towards prevention of SCC ................................................................. 53
Table 4.26: Level of knowledge in relation to practices ............................................. 53

LIST OF FIGURES

Figure 1: Diagram of Problem Analysis ................................................................. 10
Figure 2: Theoretical framework ........................................................................... 14
Figure 4.1 Definition of sickle cell crises ............................................................... 42
Figure 4.2 Sickle cell crises are preventable ............................................................... 43
Figure 4.3 Source of information on prevention of SCC ........................................ 44
Figure 4.4 Level of knowledge on prevention of SCC ............................................. 45
APPENDICES

Appendix I  Questionnaire................................................................. 72
Appendix V  Request to undertake study............................................. 78
Appendix V  Authority to undertake study.......................................... 78
Appendix II  Work Plan................................................................. 80
Appendix III Gantt chart................................................................. 81
Appendix IV Budget and Justification................................................ 83
LIST OF ABBREVIATIONS

CSO - Central Statistic Office
HBB - Hemoglobin Beta Gene
HBM - Health Belief Model
IEC - Information Education and Communication
NIH - National Institute of Health
SCA - Sickle Cell Anemia
SCC - Sickle Cell Crises
SCD - Sickle Cell Disease
SCT - Sickle Cell Trait
UTH - University Teaching Hospital
VOC - Vaso-Occlusive Crisis
WHO - World Health Organization
DECLARATION

I HILDA HAMULANDABALA hereby declare that the work presented in this study for Bachelor of Science Degree in Nursing has not been presented wholly or in part for any other degree and is not being currently submitted for any other Degree.

Signed:..........................  Date:..........................

Candidate

Approved by:..........................  Date:..........................

Supervisor

THE UNIVERSITY OF ZAMBIA
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3.0 MAY 2012

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STATEMENT

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

Signed:................................................. Date.............................................

(Student)
DEDICATION

This study is dedicated to my family and my husband for their support and encouragement during the study.
ABSTRACT

Sickle cell crises are the most cause of hospital admission in children with SCD at the University Teaching Hospital. Although there is no known cure for sickle cell disease, crises are preventable most of the times. The main objective of the study was to determine knowledge and practices of parents/caretakers with children with sickle cell disease towards prevention of sickle cell crises at Hematology clinic of the University Teaching Hospital. The study hypothesized that there is an association between knowledge and prevention of crises and the following factors: Information, Education and Communication given to parents/caretakers concerning preventive measures, level of education of a parent/caretaker and economic status of a family.

Exploratory, quantitative, non experimental study design was used. A simple random sampling method without replacement was used and data was collected using an interview schedule from fifty (50) respondents who were parents/caretakers to children with SCD at the University teaching Hospital. Data were collected, sorted, coded and entered on SPSS spreadsheet and analysed using SPSS version 16.0. Frequency tables, pie charts and cross tabulations were used for easy understanding, interpretation and to summarize a large data set in a visual form which require minimal additional explanation of the study findings.

The study revealed that 52% of the respondents had adequate knowledge on prevention of sickle cell crises. Further analysis revealed that majority (64%) of the respondents had positive practices towards prevention of crises. It was observed that 83% of the respondents who had a high family income defined as K1 000 000 and above had positive practices towards prevention of sickle cell crises as compared to 48% of the respondents who earned below K500 000 but had positive practices. Respondents who went up to secondary and tertiary level of education (84% and 83% respectively) had positive practices towards prevention of crises while all (100%) those who never went to school had negative practices. The study further revealed that 70% of the respondents who practiced cultural methods in the prevention of crises had inadequate knowledge compared to 30% who practiced cultural methods but had adequate knowledge. The study revealed that there is relationship between knowledge, economic status of the family, level of education of parents and caretakers and practices towards prevention of crises.
The study further revealed that 66% of the respondents got the information on prevention of sickle cell crises from hospital staff while 34% got from other sources. However, more than half (62%) of the respondents who indicated that information given by hospital staff was adequate had negative practices towards prevention of crises while 83% of those who indicated that they had inadequate information on prevention of crises also had negative practices. Therefore, some of the recommendations made for this study were that in order to enhance parents/caretakers’ practices towards prevention of crises, hospital staff need to demonstrate the actual practice in addition to giving IEC. This would be of help to parents/caretakers because it is easy to put observed behavior into practice. There is also need for hospital staff to ensure that all parents/caretakers are given IEC on prevention of crises on each visit to hospital/clinic as information given by hospital staff is more valid and reliable than from other sources.
CHAPTER ONE

1.0 INTRODUCTION

1.1 BACKGROUND INFORMATION

Sickle-Cell Disease (SCD) or Sickle-Cell Anaemia (SCA) is an autosomal recessive genetic blood disorder with incomplete dominance, characterized by red blood cells that assume an abnormal, rigid, sickle shape (Platt, 2008). Sickling decreases the cells’ flexibility and results in a risk of various complications. It occurs because of a mutation in the haemoglobin gene. The term disease is an umbrella term for a group of inherited hemoglobinopathies in which abnormal sickle hemoglobin (Hb S) partially or completely replaces normal adult hemoglobin. Two of the most common forms of SCD are sickle cell trait (SCT) and sickle cell anemia (SCA) (Monaha et al, 2007).

About 5% of world’s population carries the genes responsible for haemoglobin disorders and about 300,000 children are born worldwide with sickle cell disease every year. In United Kingdom, more than 200 babies are born annually with SCD. (World Health Organization, 2006).

About three quarters of sickle-cell cases occur in Africa and about 200,000 infants are born with sickle cell anemia. WHO, (2006) and Kofi et al, (2010) estimated that around 2% of newborns in Nigeria were affected by sickle cell anaemia, giving a total of 150,000 affected children born every year in Nigeria alone. In Europe, the highest prevalence of the disease has been observed in France. In 2007, 28.45% of all newborns in France had at least one parent originating from a region defined as "at risk" (mainly Africa). In the Middle East, about 6,000 children are born annually with SCD, at least 50% of these in Saudi Arabia (Awasthy et al., 2008).

According to Changufu (2005), in Zambia like any other country in Africa, 17 or more out of every 100 indigenous Zambians are carriers of the sickle cell gene, and about 200 or more out of every 10,000 births per year are infants with sickle cell anemia. In Lusaka, at the University Teaching Hospital, sickle cell disease was among the Top ten diseases causing morbidity among children in 2007 and 2008 (UTH, 2011-2013). The most affected group among children is those
between six months to five years of age. This is the age at which the first sickle cell crisis usually appears.

The term "sickle cell crisis" is used to describe several independent acute conditions occurring in patients with sickle cell disease (Weatherall and Clegg, 2001). Sickle cell crises include vaso-occlusive, aplastic, sequestration, hemolytic crises. Most episodes of sickle cell crises last between five and seven days. The commonest of these crises is the Vaso-occlusive (Muscari 2005).

Vaso-occlusive crisis is caused by sickle-shaped red blood cells that obstruct capillaries and restrict blood flow to an organ, resulting in ischaemia, pain, necrosis and often organ damage. The frequency, severity, and duration of these crises vary considerably. It is the most common cause of hospital readmissions in children and almost always occurs together with hemolytic crisis. Usually the crisis is precipitated by infection, dehydration, fever, exposure to cold, tobacco smoke and low oxygen level (Afolayan and Jolayeni, 2011).

Splenetic sequestration crisis is an acute, painful enlargement of the spleen. The sinusoids and gates would open at the same time resulting in sudden pooling of the blood into the spleen and circulatory defect leading to sudden hypovolaemia. The abdomen becomes bloated and very hard. Splenic sequestration crisis is considered an emergency. If not treated, patients may die within 1–2 hours due to circulatory failure. (Muscari 2005:208-209).

Aplastic crisis is an acute worsening of the patient's baseline anaemia, producing pallor, tachycardia, and fatigue. This crisis is triggered by parvovirus B19, which directly affects erythropoiesis (production of red blood cells) by invading the red cell precursors and multiplying in them and destroying them (Hockenberry, Wison & Winkelstein, 2005). Parvovirus infection nearly completely prevents red blood cell production for two to three days (Muscari 2005).

Haemolytic crises are acute accelerated drops in haemoglobin level. The red blood cells break down at a faster rate. This is particularly common in patients with co-existent G6PD deficiency (Hockenberry, Wison & Winkelstein, 2005).
Katibi (2008) stated that patients with sickle cell disease may have recurrent illness and be hospitalized due to various complications of the disease such as frequent attacks of sickle cell crises and other infections. The cost implication and mental agony of the parents in particular are of significance. The cost of daily maintenance of sickle cell patient is extremely huge in terms of drugs, nutrition, prevention of crises, hospitalization and that the affected individuals or families suffer a burden of anxiety, frequent illness, excess mortality rates, ignorance and lack of appropriate health services (Katibi, 2008). The consequence of the disease on the affected individual are too numerous to mention. Some of them are physical deformities such as frontal bossing, protruding abdomen, lordosis, kyphosis and thin extremities, growth retardation, chronic leg ulcers. Other effects include damaging effect of the stigma of being a sickler on his/her psyche, social withdraw, depression, low self esteem and the child being absent from school due to frequent illness (Jaffer et al, 2009).

The major causes of admission are crises. In order to reduce admissions, patients and parents with children with sickle cell disease should be educated about the nature of the disease and its treatment. The frequency and severity of complications can be significantly lessened, and quality of life enhanced, by appropriate precautions and preventive care and timely and effective treatment.

According to a research done by Jaffer et al (2009), Knowledge about sickle cell disease and predisposing factors of sickle cell crises affect attitude (behaviors and beliefs) and therefore, parents/caretakers’ knowledge regarding sickle crises preventive measures is positively correlated with their attitude toward preventive practices.

It is said that knowledge is power in that it will make an individual to act according to his/her level of understanding of the situation s/he finds himself in. Parents and caretakers who are knowledgeable about the disease are more likely to practice preventive measures. Some of the preventive measures are restricting children from physical activities demanding more oxygen, environments with low oxygen (high altitudes, non pressurized airplane flights) avoiding smoking in or around these children. In additional these parents/caretakers would ensure that children are getting enough fluids, avoiding too much exposure to the sun as this will cause dehydration, having the children vaccinated as recommended by the health care provider and
they would even share the above information with teachers and other caretakers, when necessary. Furthermore, these parents and caretakers will be giving their children prescribed drugs such as antimalarial, folic acid according to the doctor’s orders. This is in an effort to prevent and combat infection which is one of the predisposing factors to a crisis.

It is assumed that if appropriate Health Information concerning predisposing factors to crises and its prevention is given, parents and caretakers will practice the preventive measures resulting in prevention of crises and consequently reduction in frequency of admissions to hemato-oncology ward.

1.2 STATEMENT OF THE PROBLEM
Sickle cell crises are a major health problem faced by patients with sickle cell disease. Crises mostly occur in children between six months to five years. Before a child goes into a crisis there are some factors believed to precipitate crisis. These factors include dehydration, infection, hypoxia, high altitudes, and exposure to cold and vigorous exercise (Oyeyemi, 2011). According to Kofi et al, 2007, sickle cell disease contributes the equivalent of 5% to under five deaths in Africa with up to 16% in West Africa.

In Zambia’s University Teaching Hospital (hemato-oncology ward), sickle cell crises is among the Top 10 causes of morbidity. A monthly admission of 35-40 children to hemato-oncology ward indicates an increase.

Sickle cell crises are characterized by severe obstruction of blood vessels by sickled cells preventing oxygen from reaching tissues and organs; anemia results as the body breaks down damaged blood cells which have become permanently sickled; sudden pooling of the blood into the spleen and circulatory system leading to sudden hypovolaemia and also Parvovirus infection which invades the red cell precursors and multiplying in them destroying them thereby preventing new red blood cell production. Children have to be admitted to Hospital due to severe pain.

Children suffer many consequences during a sickle cell crisis, apart from the severe pain they undergo; their growth is affected, susceptible to other infections. They are usually anemic. Others include absenteeism from school due to frequent illness, damaging effect of the stigma of
being a sickler on his/her psyche, social withdrawal, depression, low self esteem. When the child is experiencing a crisis the normal family process such as routines and rituals are disrupted too. In their efforts to meet the demands related to illness very often family members are restricted from some activities or even give up. In addition, the family faces many challenges of meeting the costs of health services as a result of frequent hospitalization and other demands. Sickle cell disease is incurable but the sickler can live a normal life only if the parent and caretaker take certain precautions which aim at reducing the frequency of crises. This can only be done if the parents and caretakers are knowledgeable of the precipitating factors and are able to practice certain preventive measures.

Ministry of Health through the Association of the People Living with Sickle Cell Anemia has embarked on awareness of SCA and preventive measures of sickle cell crises. Parents and caretakers are educated on how they can prevent crises such as ensuring that the child has adequate and good nutrition, wear warm clothes, taking plenty of fluids, having the child vaccinated as recommended by the health care provider.

In addition, at Hemato-oncology ward and Hematology (clinic 4) of UTH, staff involve parents/caretakers in the care of their children by giving Information Education and Communication regarding the predisposing factors and preventive measures of sickle cell crises. IEC is offered to them when admitted to hospital and when they bring their children for review at (Hematology) clinic 4. They are given prophylaxis drugs according to sickle cell treatment protocol in order to prevent infection like malaria consequently preventing crises.

Despite the health education being given to parents/caretakers, there is an increase in children being readmitted to hospital mainly due to crises as can be seen from monthly admissions of 35-40. What cause an increase is not certainly known but there are factors that could be contributing to such increase such as inadequate knowledge and poor practices towards prevention of crises.
1.3 FACTORS THAT MAY INFLUENCE KNOWLEDGE AND PRACTICES OF PARENTS AND CARETAKERS TOWARDS PREVENTION OF SICKLE CELL CRISSES IN CHILDREN WITH SICKLE CELL DISEASE

There are various factors that may influence the knowledge and practices towards the prevention of sickle cell crises. Some factors have a direct influence while others have an indirect influence.

1.3.1 Service related factors

1.3.1.1 Staffing levels

This has an influence on the knowledge and practices of parents and caretakers towards prevention of crises in children with sickle cell disease. This is due to the fact that if there is shortage of health staff, the quality of Information Education and Communication given to parents and caretakers will be affected as they will spend little time in giving IEC. In addition this shortage may cause frustration due to work overload and in turn this will affect the quality of IEC given to the parents.

1.3.1.2 Attitude of health staff

Attitude of staff towards parents and caretakers can influence the knowledge and practices towards prevention of sickle cell crises either positively or negatively. This attitude can be influenced by other factors such as staffing levels and work overload. If staff attitude is negative towards parents and caretakers of children with sickle cell disease, then they will not seek information/advice concerning the prevention of crises. Positive attitude will influence parents and caretakers to seek advice on how to prevent crises in their children. At the same time the attitude will determine whether giving IEC to caretakers should be a priority or not. Consequently, this influences the knowledge and practices towards prevention of sickle cell crises.

1.3.1.3 Staff supervision

Inadequate staff supervision by supervisors can influence the knowledge and practices of parents and caretakers towards prevention of crises as staff may be giving inappropriate and inadequate health information regarding the prevention of sickle cell crises or factors that predisposes to sickle cell crises. For example junior staff need frequent supervision and guidance as they may not have adequate information regarding the disease. On the other hand, nurses should be supervised as they give IEC.
1.3.1.4. Information Education and Communication given to parents/caretakers

The type of IEC given to parents and caretakers will influence the knowledge and practices towards prevention of sickle cell crises. If correct and adequate information is given to parents and caretakers regarding the prevention of crises, parents and caretakers are more likely to put it into practice. However, if inadequate information is given to parents and caretakers, they are not likely to adhere.

1.3.2 Knowledge about sickle cell disease and predisposing factors to sickle cell crises

Parents and caretakers who have the knowledge about sickle cell disease and predisposing factors to crises are more likely to take recommended preventive measures of crises. Knowledge about the disease may depend on the caretaker’s level of education. Those who are literate are able to access information through reading books, journals and also can access it through internet. In addition, those who are literate grasp health information given to them more easily and are likely to put it into practice. On the other hand, those who know very little about the disease, its consequences and predisposing factors to crises may resort to practice measures that are not medically recommended.

1.3.2 SOCIO-ECONOMIC AND CULTURAL FACTORS

1.3.2.1 Past experience with sickle cell crises prevention

This has a direct influence on practices towards prevention of sickle cell crises because parents and caretakers with positive past experiences (caretakers who managed to prevent crises in the past) may use medically recommended methods to prevent future sickle cell crises such as avoiding exposing the child to extreme coldness, giving good nutrition and plenty of fluids and restricting the child to do strenuous exercises that demands more oxygen and giving prescribed prophylactic drugs to prevent infections, while those with negative past experience may use other measures to prevent crises such as taking the child to a traditional healer or giving herbs in the hope that these will prevent crises.
1.3.2.2 Level of education of parents/caretakers

Parents and caretakers who have undergone secondary and tertiary education may find it very easy to understand the health information on the predisposing factors and the preventive measures of crises and in turn may comply with medical advice and put it into their daily practices. In addition these will be able to access information in many ways such as reading books, internet and also through interaction with other people. However, those with primary or no education background will not grasp information easily and are more likely to resort to using traditional herbs thus influencing the knowledge and practices towards prevention of sickle cell crises.

1.3.2.3 Economic status of parents/caretakers

Economic status of the parents and caretakers influences the knowledge and their practices towards the prevention of sickle cell crises. This is because in most cases parents who are illiterate are more likely to be poor making it so difficult for them to access health information regarding the prevention of sickle cell crises. It is also difficult for the poor family to afford good nutrition, clothing and good housing which are all necessary for prevention of crises. However, parents who are economically sound can easily access health services and can afford a balanced meals in turn prevent infections which precipitate a crisis. These are also likely to have undergone either secondary or tertiary education.

1.3.3 Socio-cultural factors

1.3.3.1 Age of parents/caretakers

It is assumed that the older the parent and caretaker is, the more experienced and knowledgeable she or he is regarding the disease, predisposing factors and preventive measures of sickle cell crises. This is because they would use the experience gained in the past on the prevention of crises. On the other hand young parent and caretaker may lack experience and sometimes with little knowledge of the disease and preventive measures although this may depend on the level of education.
1.3.3.2 Beliefs

Parents and caretakers’ beliefs may influence the knowledge and practices towards prevention of sickle cell crises.

If a parent and caretaker believes that the child’s illness is due to witchcraft then they may not follow the medical advice given, they will prefer using traditional herbs. On the contrary, those who disregard traditional beliefs that are harmful to health may not practice or follow them. However, they may use those that are recommended or those that they know would help the child for example giving the child blood of a guinea pig mixed with milk to boast the Hemoglobin levels.
Factors that may influence Knowledge and Practice of Parents/Caretakers with Children with Sickle Cell Disease Toward...
1.5. THEORETICAL FRAME WORK

A framework is an abstract, logical structure of meaning that guides the development of the study and enables the researcher to link the findings to nursing’s body of knowledge (Burns and Grove, 2005). A study framework can be expressed as a map or a diagram of the relationships that provide the basis for a study or can be presented in a narrative format. The following model will be used to predict the health behaviors of parents/caretakers.

Health Belief Model

The Health Belief Model (HBM) is a tool that scientists use to try and predict health behaviors. The model was originally developed in the 1950s by Rosenstock and updated in the 1980s by Becker (Basavanthapa, 2008). It is based on the theory that a person’s willingness to change their health behaviors is primarily due to the following factors:

**Perceived Susceptibility:** refers to a person’s perception that a health problem is personally relevant or that a diagnosis of illness is accurate. In this case parents/caretakers believing that their children are at risk of going into sickle cell crisis because of exposure to coldness, not giving them enough fluids, not giving them prescribed drugs and not restraining them from doing exercises requiring more oxygen, they will adhere and practice preventive measures by avoiding those predisposing factors to crises.

**Perceived severity:** even when one recognizes personal susceptibility, action will not occur unless the individual perceives the severity to be high enough to have serious organic or social complications. The consequences of sickle cell crises include the child having anemia, repeated infections, retarded growth and absence from school and repeated hospitalization. If parents/caretakers perceive the consequences to be serious they are more likely to act and prevent the crises.

**Perceived benefits:** refers to the patient’s belief that a given treatment will cure the illness or help to prevent it. The benefits of practicing preventive measures are that the child will have less frequent attacks of crisis and will have a quality living. Consequently, the number of admissions to hospital will reduce hence reducing expenditures on transport to and from hospital and other related costs.
**Perceived barrier:** refers to the complexity, duration, and accessibility of the treatment. There are so many barriers that can hinder parents and caretakers from practicing preventive measures in their children.

Some of the barriers include financial limitations as parents and caretakers would not be able to travel to the hospital for reviews, treatment and accessing of information about prevention of sickle cell crises. Misconception about sickle cell disease may be a barrier as the disease may be associated with witchcraft. Such individuals are not likely to practice preventive measures because of their beliefs. Furthermore, parents and caretakers with low education levels have difficulties in understanding information concerning sickle cell disease and preventive measures therefore, will prefer using non-medically recommended practices.

**Cue to action:** these are factors that activate one’s inner drive to change or make someone ready to change. There are external events that prompt a desire to make a health change for example posters about sickle cell, presentation on Television/radio set about the benefit of practicing preventive measures. A visit by Sickle Cell Association would give encouragements to parents to have a positive attitude towards prevention of sickle cell crises. For those who are literate, reading magazines or books or having a child of a relative dying from sickle cell crisis or complication of sickle cell disease will prompt parent/caretaker to institute the preventive measures.

**Self-efficacy** beliefs are cognitions that determine whether health behavior change will be initiated, how much effort will be expended and how long it will be sustained in the face of obstacles and failures. Self-efficacy influences the effort one puts to change risk behavior and the persistence to continue striving despite barriers and setbacks that may undermine motivation. The confidence that parents and caretakers have will drive them to practice preventive measures. These measures include increasing intake of nutritious foods, prevent child from doing activities demanding more oxygen and ensuring that these children sleep under a mosquito net to prevent malaria which would later precipitate a crisis. Change in parents can only come if correct information regarding the disease and its consequences are given and can be achieved through constant health education.
Predicted relationship

The Health Belief Model assumes that people are more likely to change their behavior if:

- They know what the behavior is and how to perform it (knowledge)
- They feel they are in control of the behavior and have the relevant skills.
- They observe the behavior being practiced by people they consider to be role models
- The behavior is reinforced and encouraged

Therefore, parents and caretakers are more likely to have positive practices towards prevention of sickle cell crises if they have relevant knowledge on prevention of crises. This can be achieved through regular giving of IEC on the importance of preventing sickle cell crises.
Figure 2 Diagram of the Health Belief Model

<table>
<thead>
<tr>
<th>Individual’s perception</th>
<th>Modifying factors</th>
<th>Likelihood of action</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived benefit of preventing sickle cell crises (less attacks of crises, less number of admissions) Minus barriers to prevent sickle cell crises (financial, lack of IEC, misconceptions).</td>
<td></td>
<td>Likelihood of practicing preventive measures of sickle cell crises.</td>
</tr>
</tbody>
</table>

Perceived susceptibility/perceived seriousness. Parents/caretakers perceive their children are susceptible to sickle cell crises.

PERCEIVED THREAT OF SICKLE CELL CRISSES

Cues to action
Mass media information, print and electronic media. (Information on preventive measures of sickle cell crises). A visit by Sickle Cell Association would give encouragements to parents to have a positive attitude towards prevention of sickle cell crises

Reading from books or having a child of a relative dying from complication of SCD will prompt parents/caretakers to institute the preventive measures.
1.6 JUSTIFICATION OF THE STUDY
Sickle cell crises are one of the commonest causes of admissions to hemato-oncology ward of the UTH in children. Sickle cell crises are preventable if appropriate preventive measures are given and adhered to by the parents and caretakers of affected children. The prevention of crises depends on the knowledge that the caretaker has concerning the disease and its consequences on the child. If parents and caretakers know the predisposing factors to a crisis then they will practice preventive measures to avoid a child going into a crisis.

The purpose of this study was therefore, to determine knowledge and practices of parents and caretakers towards the prevention of sickle cell crises in children at hematology (clinic 4) of UTH.

The findings helped suggesting recommendations that focus on the involvement of all the stakeholders (schools, sickle cell associations) who should participate in dissemination of information on preventive measures for sickle cell crises. The concerned health care professionals will also benefit in designing educational programs and protocols which aim at increasing the sickle cell patients' and parents and caretakers' awareness of preventive measures to crises. Furthermore, it will assist sickle cell patients and parents and caretakers (through Sickle Cell Association) to participate in awareness programs concerning crises prevention.

1.7 RESEARCH OBJECTIVES
Research objectives are clear, concise, declarative statements that are expressed in the present tense (Burns and Grove, 2005).

1.7.1 General objective of the study
To determine the knowledge and practices of parents and caretakers towards prevention of sickle cell crises in children with sickle cell disease at the University Teaching Hospital.

1.7.2 Specific objectives of the study
1.7.2.1 To assess if knowledge of parents and caretakers on prevention of sickle cell crises has influence on practices towards prevention of crises.
1.7.2.2 To determine if Information Education and Communication influences the knowledge and practices of parents and caretakers towards prevention of sickle cell crises.
1.7.2.3 To determine if staff attitude influences knowledge and practices of parents and caretakers regarding prevention of sickle cell crises in children.

1.7.2.4 To assess if the level of education of parents/caretakers has influence on their knowledge and practices towards prevention of sickle cell crises.

1.7.2.5 To determine if the economic status of the family influences knowledge and practices of parents/caretakers with regard to prevention of sickle cell crises.

1.7.2.6 Establish if social-cultural beliefs/practices have influence on the knowledge and practices of parents/caretakers with children with SCD.

1.8. HYPOTHESES

A hypothesis is a prediction about the relationship between two or more variables in a research study (Basavanthappa, 2007). The following are the hypotheses in this study.

1.7.1 The adequate the Information, Education and Communication given to parents and caretakers concerning preventive measures, the more likely that they will have adequate knowledge and positive practices towards the prevention of sickle cell crises.

1.7.2 The higher the level of education of a parent and caretaker, the more likely s/he will have adequate knowledge and positive/good practices towards the prevention of sickle cell crises.

1.7.3 The higher the economic status of a family, the more likely s/he will have positive practices towards prevention of sickle cell crises in children.

1.7.4 The more knowledgeable parents and caretakers are concerning preventive measures the more likely that they will have positive practices towards the prevention of sickle cell crises.

1.9. CONCEPTUAL DEFINITIONS OF TERMS

1.9.1 Sickle cell disease: is a group of inherited disorders of mutant Hemoglobin (HbS) that causes the characteristic sickling of red blood cells (Black & Hawks, 2009)

1.9.2 Sickle cell crises: are acute episodic condition that occurs in children with SCD such as vaso-occlusive crisis resulting from the aggregation of misshapen erythrocytes or anemia, resulting from bone marrow aplasia, increased hemolysis, folate deficiency or splenic sequestration of erythrocytes” (Dorland’s Medical Dictionary for Health, 2007).
1.9.3 Knowledge: is the information, understanding and skills that you gain through education or experience (Hornby, 2006).

1.9.4 Practice: This is the way of doing something that is the usual or expected way in a particular situation or organization (Hornby, 2006).

1.10 VARIABLES
Variables are qualities, properties or characteristics of a person, things or situations that change or vary in a study (Burns and Grove, 2005). Variables have been classified into a variety of types to explain their use in research. The types of variables defined here are independent and dependent variable.

Dependent variable—is the response, behavior, or outcome that the researcher wants to predict or explain. Changes in the dependent variable are presumed to be caused by the independent variable (Burns and Grove, 2005).

Dependent variables were:
- Knowledge of parents/caretakers on prevention of sickle cell crises
- Practices of parents/caretakers towards prevention of crises

Independent variable —is a stimulus or activity that is manipulated or varied by the researcher to create an effect on the dependent variable (Burns and Grove, 2005).

Independent variables were:
- Information, Education and Communication given to parents/caretakers,
- Level of education of parents/caretakers
- Economic status of a family
- Social and cultural beliefs/practices towards prevention of sickle cell crises

17
<table>
<thead>
<tr>
<th>VARIABLES</th>
<th>CUT OFF POINT</th>
<th>INDICATOR</th>
</tr>
</thead>
<tbody>
<tr>
<td>DEPENDENT VARIABLES</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knowledge on prevention of sickle cell crises</td>
<td>Adequate</td>
<td>If a parent/caretaker is able to mention at least five or more preventive measures of sickle cell crises such as giving plenty of fluids, restricting the child of strenuous exercises demanding more oxygen, having the child vaccinated, giving the child nutritious food, giving folic acid and antimalarial drugs, avoiding passive or active smoking in or around a child, avoiding high attitude, dress the child in warm clothes.</td>
</tr>
<tr>
<td></td>
<td>Inadequate</td>
<td>If a parent/caretaker mentions four or less preventive measures of crises such as giving fluids, dress the child in warm clothes and restrict the child of doing strenuous exercise demanding more oxygen</td>
</tr>
<tr>
<td>Practices of parents/caretakers towards</td>
<td>Good</td>
<td>If a parent/caretaker mentions that she/he practices at least five preventive measures such as giving the child nutritious food and plenty of fluids, dressing the child warm clothes, giving prophylactic drugs, and taking the child to clinic for review, ensuring that the child sleep under mosquito net and restricting the child of strenuous exercises demanding more oxygen.</td>
</tr>
<tr>
<td>prevention of crises</td>
<td>Poor</td>
<td>If a parent/caretaker mentions that s/he does not give the child nutritious food, take the child for review and does not dress the child warm clothes.</td>
</tr>
<tr>
<td>INDEPENDENT VARIABLES</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information Education and Communication</td>
<td>Adequate</td>
<td>If a parent/caretaker indicates that correct and adequate information is given regarding prevention of sickle cell crises.</td>
</tr>
<tr>
<td>given to parents/caretakers</td>
<td>Inadequate</td>
<td>If a parent/caretaker indicates that information given regarding the prevention of sickle cell crises is not enough.</td>
</tr>
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<td></td>
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<td>16 &amp; 17</td>
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18
<table>
<thead>
<tr>
<th>Level of education of parents/caretakers</th>
<th>High</th>
<th>If a parent/caretaker has attained college or university</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Medium</td>
<td>If a parent/caretaker has attained secondary education</td>
</tr>
<tr>
<td></td>
<td>Low</td>
<td>If a parent/caretaker has never been to school or has attained primary education</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5</td>
</tr>
<tr>
<td>Family income</td>
<td>High</td>
<td>If a family has an income of above K1,000,000 per month</td>
</tr>
<tr>
<td></td>
<td>Medium</td>
<td>If a family has an income of K500,000 to K999,000 per month.</td>
</tr>
<tr>
<td></td>
<td>Low</td>
<td>If a family has an income of below K500,000 per month.</td>
</tr>
<tr>
<td>Social and cultural beliefs</td>
<td>Negative</td>
<td>If a parent/caretaker has social and cultural beliefs that she practices towards prevention of sickle cell crises</td>
</tr>
<tr>
<td></td>
<td>Positive</td>
<td>If a parent/caretaker has no social and cultural beliefs that she practices towards prevention of sickle cell crises</td>
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<td></td>
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<td>19,20 &amp; 21</td>
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CHAPTER 2
2.0 LITERATURE REVIEW

Literature review is a broad, comprehensive in-depth, systematic and critical review of scholarly publications, unpublished scholarly print materials, audiovisual materials and personal communication (Basavanthappa, 2006). The purposes for analyzing or reviewing existing literature is to generate research questions, to identify what is known and not known about a particular research problem or situation. In short literature review conveys to the reader what is currently known regarding the topic of interest (Burns & Grove, 2005).

The aim of the study was to determine the knowledge and practices of parents and caretakers with children with sickle cell disease towards the prevention of sickle cell crises at the University Teaching Hospital. The reviewed literature was from books, published articles from journals and unpublished articles. The reviewed Literature was discussed according to the dependent and independent variables which were knowledge and practices, IEC, Family income towards the prevention of sickle cell crises.

Sickle cell disease (SCD) has recently been recognized as a major public health problem by World Health Organization. According to WHO Report (2006), SCD is considered as one of the most prevalent hereditary hematological disease worldwide with about 300 000 children born with the disease every year. It is found in many parts of the world; with the highest frequency of the disease among people with ancestry in malaria-stricken areas, the tropical regions particularly sub-Saharan Africa, India, Jamaica and the Middle-East. The geographic distribution of the sickle-cell trait is very similar to that of malaria. The sickle cell trait has a partial protective effect against malaria, and this may explain why sickle cell has been maintained at such high prevalence levels in tropical Africa. Those who inherit the gene from both parents do not have this protection. In addition, they suffer from severe effects of SCD and many die before they reach reproductive age. Despite the fact that 70% of sufferers live in Africa, expenditure on the related care and research in the continent is negligible and most advances in the understanding and management of this condition have been based on research conducted in the North (WHO, 2006).

With regard to mortality, evidence from studies conducted in the North, show that the highest levels
of SCD-related mortality occur in children aged between 6 months and 3 years, the commonest causes of death being acute chest syndrome, acute splenic sequestration and pneumococcal septicaemia (WHO Report, 2006). This indicates that people and the communities need to be given health education on the relationship between malaria and sickle cell disease so that they can ensure that their affected children sleep under treated mosquito nets and are given drugs for treatment. This intervention if implemented it would help reduce the frequency of sickle cell crises subsequently reduce mortality rate for children with sickle cell disease.

According to Diallo, (2002), Africa is the most highly affected continent with 200,000 new born affected by sickle cell anemia per year. This constitutes approximately 66.6% of the children born with haemoglobinopathies worldwide. In Africa when health impact is measured by under-five mortality, sickle-cell anaemia contributes the equivalent of 5% of under five deaths on the African continent, more than 9% of such deaths in west Africa, and up to 16% of under-five deaths in individual west African countries. The prevalence of SCD in Uganda is believed to be the highest in the whole world and it accounts for approximately 16.2% of all pediatric deaths. According to WHO reports (2006) from Ghana, it is estimated that 15,000 children are born with sickle cell disease annually. In Benin, the sickle cell trait prevalence is estimated to be 25% while in Nigeria it ranges from 24-25%. In Zambia, the trait average is 15.3% and in Tanzania on the other hand ranges from 2%-38%. These findings can help sensitize the people in areas where the prevalence rate is high on how the disease is acquired and how to prevent it. This can be done through conducting research that would come up with possible solution to the problem such as designing awareness programmes regarding the preventive measures of sickle cell crises.

2.1 Knowledge on prevention of sickle cell crises

According to a study conducted in India by Balgir (2010), entitled Intervention and Prevention of Hereditary Hemolytic Disorder; an experience from Knowledge, attitude and Practice studies indicated that in a pre intervention, 97% respondents did not know about sickle cell disease and only 2.1% knew. All did not know about sickle cell crises and precaution to take to prevent them. After the intervention (IEC) 83.6% were able to explain what sickle cell disease, sickling and precautions to take to prevent it. This means that people would be able to prevent the crises if they
know the factors that precipitate and precautions to take to prevent them. Therefore, there is need to intensify health education to people which should be directed towards prevention of sickle cell crises.

In another study conducted by Jaffer, et al (2009), in Bahrain entitled Adult Sickle Cell Diseased Patients’ Knowledge and Attitude toward the preventive measures of sickle cell disease crisis, it was revealed that 38% had little knowledge about SCD, 32% had moderate knowledge and 30% had high degree of knowledge. The author recommended that mild SCD crisis can be managed in the primary health care clinic or at home if the patient is given adequate education about their disease and that there is need for a strong health education campaign about SCD. In the same study it was indicated that there are many factors participating in SCD crises. Factors found were exposure to cold 45%, fever 35%, exhaustion 35%, temperature change 19%, hot weather 10%, over crowding 10%, psychological tension 10%, vomiting and diarrhea 7% and traveling by air 1%. This indicates that people would be able to prevent crises if they knew the precipitating factors. It is therefore, recommended that more emphasis should be directed towards educating the people on the precipitating factors to a crisis and how these factors can be prevented. Jaffer, et al, further stated that 11 areas were identified as domains that are essential for prevention of SCD crises. These domains are general precaution, exercise, food, rest, travel, places, weather, and medication, emotional, social, spiritual and coexisting medical condition. It is believed that these general precautions once followed have proven to be effective in the prevention of crises. This still indicates that health education should constantly be given to people to remind and encourage them to employ the simple and cheap but effective preventive measures of crises using locally available resources.

Studies conducted in Africa by WHO (2006), revealed that parents/caretakers and patients’ have inadequate information on how to prevent sickle cell crises and that there is need for a strong health education campaign strategy that would help people acquire knowledge pertaining to the disease. The sickle cell crises consequences might be preventable if the parents/caretakers of children with sickle cell disease and patients become adherent to the preventive measures and this can be achieved through adequate health education.

In sub-Saharan Africa mortality is much higher because of the geographical distribution since malaria and SCD share the same geographical distribution (WHO, 2006). In areas where the incidence of
malaria is high so is sickle cell disease. Other factors include high poverty levels, inadequate prophylaxis and treatment of infections, and inadequate health information to the parents and the community at large. This entails that all involved ministries of health, research organizations and international agencies and governments need to work together to develop a clear strategy that should solve these challenges. It is therefore, the responsibility of the involved organizations to ensure and source enough resources that should be allocated towards putting up programmes aimed at educating people through health education. The health education should be directed towards imparting knowledge on the predisposing factors of sickle cell crises and on how to prevent them.

In a research conducted in Nigeria entitled Parental Attitude to Children with Sickle Cell Disease by Whitehead et al, (2010), which revealed that most of the crises faced by children with SCD could have been prevented or better managed if their parents had knowledge of newborn screening. Review of the literature shows that most parents are unaware of newborn screening unless their infant has had an abnormal result. Parents who are aware of the screening are not knowledgeable about the process of reporting screening result or the conditions for which newborns are screened. The recommendations were that health education should be intensified apart from putting up screening services. This is important in that if parents are aware of these services they would seek advice and early interventions would be put in place.

In Zambia like any other countries in Africa, sickle cell anemia is one of the commonest hereditary diseases. UTH (2011) admissions for children from sickle cell crises were attributed to inadequate knowledge and bad practices towards prevention of sickle cell crises. These admissions could have been prevented if the community had adequate knowledge and used good practices towards the prevention of sickle cell crises.

Zambia being a poor country is greatly faced with serious challenges in terms of IEC dissemination to the public to help improve on knowledge and practices of parents and caretakers towards prevention of sickle cell crises in children.
2.2 Practices on prevention of Sickle Cell Crises

World Health Organization, (2006), indicated that sickle cell crises are preventable if preventive measures are put in place. WHO aims at making sure that there is access to information regarding the prevention of crises to everyone so that they are able to manage the disease at home. This is done through giving health education to parents/caretakers on predisposing factors and prevention of sickle cell crises. In places where parents/caretakers are knowledgeable about the preventive measures, children with sickle cell anemia lead normal lives. This is because parents/caretakers take precautions to reduce sickle cell crises by restricting children with the disease from participating in physical activities demanding more oxygen, avoiding environments with low oxygen (high altitudes, nonpressurized airplane flights). Furthermore, they avoid smoking in/around the children, avoiding known sources of infection and quick treating. They make sure that the child is getting enough fluids, to avoid too much exposure to the sun, to recognize signs of dehydration have the child vaccinated as recommended by the health care provider and share the above information with teachers and other caretakers. It is evident that in countries where there is improved IEC given to the people, the frequencies of sickle cell crises are reduced (WHO, 2006).

According to WHO, (2006), children with sickle cell disease from the age of 6 months up to 5 years should be receiving antibiotic, folic acid and antimalarial to prevent infections as infections are a major triggering factor to a crisis. Parents and caretakers follow instructions on how to give these drugs and it has proved to be a very effective practice of preventing crises. Children who receive these drugs are less likely to have frequent crises. Another positive practice that parents and caregivers need to do is to ensure that children with sickle cell disease sleep under mosquito nets to prevent them from mosquito bites and consequently malaria. The government has to ensure that mosquito nets are available for these children and given free of charge. Unfortunately, many countries do not have such policies and so children are not able to be given these drugs.

In a study conducted by Balgir, (2010) in India entitled Intervention and Prevention of Hereditary Hemolytic Disorder; An experience from Knowledge, attitude and Practice studies, stated that people’s attitude towards sickle cell disease pre intervention (before giving IEC) did nothing about it or will automatically be cured (100%). About 57% of the respondents were of the opinion to take illness very lightly or let the person die attitude.
Most of the people used traditional herbs (96.5%) at home to prevent and treat the disease. This study indicated that there was poor practice towards prevention of sickle cell crises. The IEC booklets were supplied free to the communities for future guidance and practice. Post intervention (IEC and booklets given) results showed that people were aware of the precautions to be taken to prevent crises. About 65.7% had realized that something should be done. It was better to go to a doctor for treatment or where advice on what to do can be given. Therefore, parents and caretakers can have positive attitude towards practicing of preventive measures if only they have the correct information regarding the prevention of sickle cell crises.

Jaffer et al, (2009), indicated that there are several ways sickle cell patients' and parents might undertake to limit crises occurrence. Parents and caretakers should avoid cigarette smoke; both active and passive smoking as smoke damage the lungs and lower oxygen levels in the blood for children and adults who have sickle cell disease. In addition, a link between cigarette smoking and "acute chest syndrome" in sickle cell anemia is suggested. Keeping balance between activity and rest is crucial for sickle cell patients. Therefore, parents and caretakers should discourage their children from those exercises demanding more oxygen leading to exhaustion. Moderate exercise is unlikely to cause harm in people with sickle cell disease. Strenuous exercise is suspected to lead to factors that may precipitate sickle cell crisis, such as low tissue oxygen saturation, dehydration. People who have this disease should try to avoid activities that reduce the amount of oxygen in their blood. Consuming nutritious food is helpful in sickling prevention. If parents and caretakers practice the above measures to prevent sickle cell crises, the frequency of sickle cell crises attacks would reduce.

According to WebMD, (2005) an improvement in the patient's condition was noted with increased fluids, fruits, vegetables and milk consumption. Children should be vaccinated during childhood against Streptococcus pneumonia; Haemophilus influenzae as infection is one of the precipitating factors to crisis. Penicillin prophylaxis has dramatically reduced infection related mortality in SCD patients. Improved preventive measures such as pneumococcal vaccines for infants may reduce the number and cost of sickle cell related hospitalizations in the future.

If parents/caretakers follow the recommended measures they can help prevent sickle cell crises and improve the lives of sicklers. This goes with the amount of knowledge a parent/caretaker has regarding sickle cell disease and its consequences to the child. Parents/caretakers who are
economically sound and have adequate knowledge are able to prevent the crises. This is so because they are able to go to hospital for reviews and are given advice on how to manage the disease at home. In addition, these parents and caretakers are able to buy nutritious food for their children and warm clothes.

In Zambia, no study has been conducted specifically looking at knowledge and practices of parents towards prevention of sickle cell crises in children with sickle cell disease but other studies related to mortality, coping mechanisms have been done. Therefore, there is little information known concerning parents and caretakers’ knowledge and practices towards prevention of sickle cell crises. The Association of sickle cell anemia is working in conjunction with Ministry of health where they put emphasis on educating the public on measures which are simple to carry out in order to prevent crises in children. These measures include; dressing children in warm clothes, give children plenty of fluids, restrict children from strenuous exercises, give good nutritious foods, taking children to hospital for medical review, and give prescribed medication (Changufu, 2005). It is believed that knowledge is the key factor for positive practice and this call for health education programs directed at empowering parents and caretakers to have positive attitude towards prevention of sickle cell crises.

2.3 Information, Education and Communication on prevention of sickle cell crises

Information, Education and Communication (IEC) in health programmes aims to increase awareness, change attitudes and brings about a specific behavior. In this context IEC is given to increase parents/caretakers’ knowledge and promote positive practices towards prevention of sickle cell crises.

According to a study conducted by Milosavljevic et al, (2007) on Experiences of the Caregivers in Managing the Disease in Children Living in the Western Region of Jamaica, states that education is essential in helping to improve the quality of life of any sick person. When attending the sickle cell clinic for the first time, parents/caretakers were given very clear information about the disease and how to manage the disease at home. With such a system in place, parents/caretakers are expected to know the basic facts about the disease and how to prevent some unwanted complications such as crises. Respondents stated that when a crisis arises, the best thing is not to panic but remember what they have been taught at the clinic. The study further stated that their knowledge came mostly from
education and reinforcement from doctors and nurses at the clinics. It is important that correct information regarding the prevention of sickle cell crises is given to parents to compare them with positive practices. It is also during health education that misconceptions about the cause and nature of the disease can be clarified.

In another related study conducted by Jaffer et al as indicated earlier it was recommended that mild SCD crisis can be managed at home if the patients are given adequate education about the disease. Therefore, IEC is an important factor and there is need for a strong health education campaign on SCD in order to sensitize the parents/caretakers on the nature of the disease and how crises can be managed at home. People acquire knowledge in so many ways and one of these is through Information, Education and Communication given to by medical personnel. This means that if parents are given adequate health information on crises prevention then their knowledge will increase in turn influence their practices towards prevention.

2.4 Economic status of parents/caretakers towards prevention of sickle cell crises

Parents/caretakers who are economically sound find it easy to practice preventive measures of sickle cell crises. This is because they are able to meet the daily requirement of their children. These daily requirement include buying nutritious food, fruits, prescribed drugs and buying warm clothes for their children and accessing health care services. Katibi (2008) indicated that the cost of daily maintenance of sickle cell patient is huge in terms of drugs, nutrition, prevention of crisis, hospitalization and that the affected individuals or families suffer a burden of anxiety, frequent illness, excess mortality rates, ignorance and lack of appropriate health services.

In another study conducted by Kofi et al as indicated earlier stated that people who are illiterate and poor are subjected to economic exploitation, deprivation and social isolation which are reflected in their low quality of life. This implies that those who are poor or have low family income are unable to implement preventive measures even if they may have adequate knowledge on prevention of sickle cell crises. This therefore, entails that for parents/caretakers to be able to practice preventive measures they should have enough resources to enable them meet the daily demands of their children.
2.4. Conclusion

The benefits of preventing sickle cell crises go far beyond reducing the frequent of admission to hospital. Literature review has shown that Information, Education and Communication is key to acquiring knowledge on preventive measures for sickle cell crises. Literature review established that if individuals have inadequate knowledge on sickle cell disease, the precipitating factors to a crisis and the preventive measures, this will affect their practice. It is for this reason that the investigator desired to determine knowledge and practices of parents/caretakers with children with sickle cell disease towards the prevention of crises. The link between parents/caretakers’ knowledge and practices was uncovered. The results would help the staff at UTH to design awareness programmes regarding the preventive measures of sickle cell crises for the people. It is evident that increasing the knowledge of sickle cell patients and parents/caretakers regarding prevention of crises would potentially affect their practices towards crises prevention thus reducing the suffering of children during a crisis.
CHAPTER 3

3.0 RESEARCH METHODOLOGY

Research methodology refers to steps, procedures and strategies for gathering and analyzing data in research investigations (Polit, Beck and Hungler, 2001). The purpose of the study was to determine knowledge and practices of parents/caretakers with children with sickle cell disease towards prevention of sickle cell crises at hematology clinic of the University Teaching Hospital. The methodology cover research design, study setting, study population, sample selection, sample size, data collection tools, data collection technique, pilot study, validity and reliability, ethical and cultural considerations, data analysis and plans for dissemination of findings.

3.1 Research Design

Research design is the plan, structure and strategy of investigations of answering the research question and is the overall plan or blue-print the researcher selects to carry out their study (Basavanthappa, 2006). The research design provides an explicit blueprint of how research activities will be carried out and its objective is to answer the research question. The correct design helps to isolate items of concern so that they can be examined under known conditions, it eliminates bias and reduces margin error and enables the researcher to state confidently conclusions on which to base future decisions (Basavanthappa, 2006).

The investigator in this study used an exploratory study design. Exploratory study is a type of nonexperimental research design that collects descriptions of existing phenomena for the purpose of using the data to justify or assess current conditions or to make plans for improvement of conditions (Lobiondo-Wood and Haber, 2006). The word “explore” implies scrutinizing unknown regions for the purpose of discovery. An exploratory study is a small-scale study of relatively short duration, which is carried when there little known about a situation or a problem (Basavanthappa, 2006). Therefore, an exploratory study design was suitable for this study because of the limited resources and time allocated for the study. It was also suitable because there is little known about knowledge and practices of parents and caretakers with children with SCD towards prevention of crises at the University Teaching Hospital. This design helped the investigator to establish the extent to which
parents and caretakers with children with sickle cell disease knew about the prevention of sickle cell crises.

3.2 Research setting

The research setting is the environment or location where a research study is carried out or conducted (Burns & Grove, 2005). The study was conducted at the University Teaching Hospital which is the largest referral hospital in Zambia. As a national referral hospital the catchment is the entire country though the bulk of the patients that are seen at UTH come from within Lusaka province with few referred from the countryside.

The study was conducted in the Hematology (clinic 4) of the University Teaching Hospital. The clinic was chosen because it had the participants with characteristics which were the criteria of the study that is parents/caretakers with children with sickle cell disease.

3.3 Study population

Study population refers “to total category of persons or objects that meets the criteria for study established by the researcher” (Basavanthappa, 2008). In this study, the study population included all parents/caretakers to children (children below 14 years) with sickle cell disease. The main study was conducted at hematology or clinic 4 on parents and caretakers who were bringing their children for review at the time of the study. Parents and caretakers were able to give information on their knowledge and practices towards prevention of sickle cell crises because they were the primary caregivers for children with sickle cell disease.

3.4 Sample selection

Sampling is “the process of selecting representative units of a population for study in a research or it is the process of selecting a subset of a population in order to obtain information regarding a phenomenon in a way that represents the entire population” (Basavanthappa, 2008). The participants in this study were selected using the simple random sampling method which is the most basic of the probability sampling designs where every member of the population had an equal chance of being selected into the sample (Basavanthappa, 2008).

In this type of sample, sampling was done without replacement so that no participant would appear more than once in the sample. 100 pieces of papers numbering from 1 to 100 were written and folded.
Same papers were being used on a daily basis until the participants were 50 meaning 100 papers were picked. The papers were of the same size, colour and shape. The pieces of paper were put in a box and mixed thoroughly together by shaking the box. All those parents and caretakers who were picking even numbers were included in the study while those who picked old numbers were excluded.

3.4.1 Inclusion criteria

Burns and Grove (2005) define inclusion criteria as the ‘characteristics that the subject or element must possess to be part of the target population’. Participants who were included in the study were all parents and caretakers to children below 14 years with sickle cell disease who were attending hematology clinic at UTH.

3.4.2 Exclusion criteria

Exclusion criteria are those characteristics that can cause a person or element to be excluded from the target population (Burns and Grove, 2005). The exclusion criteria included all parents and caretakers who were coming from outside Lusaka because this study was looking at parents and caretakers who live in Lusaka.

3.5 Sample size

A sample size is a subset or portion of a population to represent the entire population in order to obtain information regarding a phenomenon (Basavanthappa, 2008). A total of 50 parents and caretakers with children with sickle cell disease were sampled from hematology clinic. The size was influenced by resource constraints that was, limited time, and inadequate human and financial resources. It was also the recommended number for attainment of the Bachelor of Science Degree in Nursing at the University of Zambia.

1.6 OPERATIONAL DEFINITIONS

Operational definition is the description of how variables or concepts will be measured or manipulated in a study (Burns and Grove, 2005). The following are operational definitions for this study;
1.6.1 Sickle cell disease: it is a term used to describe all disorders characterized by red blood cells containing abnormal sickled hemoglobin.

1.6.2 Sickle: any individual who has the sickle cell disease.

1.6.3 Sickle cell crises: episodes experienced by the patient when there is a reduction of oxygen flow to the tissue precipitated by anemia, infection, dehydration or sickled blood cells block blood vessels.

1.6.4 Knowledge: The information that a parent/caretaker has on the prevention of sickle cell crises in children.

1.6.5 Practice: the actual steps a parent or caretaker takes to prevent sickle cell crises.

1.6.6 Children: A person below the age of 14 years.

1.6.7 Parent: Any individual who has a child with sickle cell disease, either a father or mother.

1.6.8 Caretaker: Any person responsible for the care of a child with sickle cell disease.

1.6.9 Readmission: having been admitted to hemato-oncology ward at least more than once in a year.

1.6.10 Morbidity: sickness due to sickle cell crisis.

1.6.11 IEC: Health information given to parents/caretakers on prevention of sickle cell crises.

3.7 Data collection tool

This is an instrument used to gather information needed to address a research problem. It may take the form of questionnaire or interview schedule, checklist, focused group discussion guide or some other type of tool for eliciting information (Burns and Grove, 2005). In this study an interview schedule was used to collect data and it was carried out between October and November, 2011. The tool contained both closed and open ended questions which helped the researcher to explore parents and caretakers' knowledge and practices towards prevention of sickle cell crises. The interview schedule was divided into sections. Section A contained questions on Biodemographic data; section B had questions on socio-economic status of respondents. Section C had questions on knowledge of parents and caretakers with children with sickle cell disease on the prevention of sickle cell crises; section D contained questions on practices towards prevention of sickle cell crises and Section E contained questions on social and cultural practices of parents sand caretakers with children with sickle cell disease on the prevention of sickle cell crises. Finally, there was a provision where parents and caretakers were requested to suggest on how knowledge and practices towards prevention of sickle cell crises can be improved.
3.7.1 Interview schedule

An interview schedule is a questionnaire that is read to the respondent. Questionnaires are paper and pencil instruments designed to gather data from individuals, usually in a written form (Lobiondo-Wood and Haber, 2006). In this study, the interview schedule enabled the researcher to obtain data from both the literate and illiterate parents and caretakers by asking them questions.

Some of the advantages of interview schedule are suitability for both literate and illiterate respondents; it permits clarification of questions and has a higher response rate than written questionnaire. However, interview schedule has disadvantages such as the presence of the researcher might influence the response of respondents and reports of events may be less complete than information gained through observation. Therefore, in order to calm and gain cooperation from the respondents, the researcher introduced herself, created rapport with them and thoroughly explained the purpose of study.

The reason for using this type of tool was to eliminate any kind of biases associated with educational levels as parents and caretakers who were not able to read and/or write were also given the chance to participate in the study through face to face interview using the questionnaire.

3.7.2 Validity

Validity refers to whether a measurement instrument accurately measures what it is supposed to measure (Lobiondo-Wood and Haber, 2006). When an instrument is valid, it truly reflects the concept, it is supposed to measure. Validity comprises internal and external validity. Internal validity refers to interpretation of the findings within the study or data collected. It is concerned with the extent to which conclusions can be drawn about the effects of one variable on another e.g. independent on the dependent variables. To ensure validity the same questions were asked to all research participants and those questions were made simple, concise and brief and interpreted into the language each parent and caretaker was comfortable with at the time of data collection.

External validity refers to the degree to which other environmental or external factors influence the results of the study (Basavanthappa, 2008). To ensure external validity, selection of an appropriate study design, careful designing and pre-testing of the interview schedule was done.
Validity in general was ensured by conducting a pilot study at Hemato-oncology ward where simple random selection of study participants was done to avoid biases. This was done in order to ensure that the instrument measured what it was supposed to measure. After pre testing, data collection tool was corrected making it simple to both research and respondents. Corrections were made to the tool by removing questions that were confusing respondents on knowledge and modification of questions were done especially those that had “if yes or no” as those restricted the respondents from responding to the questions that followed. Open-ended questions ensured validity of the tool as those questions gave the participants an opportunity to respond in their own words. Furthermore, the researchers listened very carefully and also recorded accurately the participant’s responses to ensure validity as well.

3.7.3 Reliability

Reliability of the research instrument is the extent to which the instrument yields the same results on repeated measures. Reliability is concerned with consistency, accuracy, precision, stability, equivalence and homogeneity (Lobiondo-Wood and Haber, 2006). To ensure reliability of the instrument (interview schedule) a pilot study was conducted in the setting with similar characteristics as to the setting the main study was to be carried out in order to test the degree of accuracy.

3.8 Data collection technique

Data Collection Technique is a procedure of collection of data needed to address a research problem (Polit and Hungler, 2001). Permission to carry out the research in the Hospital was obtained from the Senior Medical Superintendent of the University Teaching Hospital, Head of Pediatric Department and also from the Nursing Officer for Pediatrics and the sister in charge for hemato-oncology ward and clinic 4 for pilot and actual study respectively.

Interview schedule was used to collect data from parents and caretakers at hematology or clinic 4, before their children were reviewed. The reason for interviewing them before the children were reviewed was because of a series of investigations after the children have been seen and also was done to avoid keeping them for so long at the clinic. This is because long stay leads exhaustion and dehydration consequently precipitating a crisis. At the clinic, the researcher asked for a room to ensure privacy to the respondent. The dress code was casual to avoid distracting the respondents. The
respondents were being welcomed and offered seat and each respondent was interviewed at a time. Respondents were greeted and self introduction to the respondents was done. An explanation of the purpose of the study was done and then verbal consent to ask questions was obtained. The researcher explained to the respondents that the interview involved answering questions from the interview schedule and that it was going to take 15 to 20 minutes. The respondents were reassured of confidentiality and anonymity by not asking their names or indicating it on the interview schedule. The respondents were informed that they were free to consent or not to consent to be interviewed. The researcher thanked the respondents for their time and information they gave after the interview.

3.9 Pilot study

A pilot study is a smaller scale of the parent study with similar methods and procedures that yield preliminary data that determine the feasibility of conducting a larger scale study and establish that sufficient scientific evidence exists to justify subsequent, more extensive research (Lobiondo-Wood and Haber, 2006).

The reason for conducting a pilot study was to assess the feasibility of the study and methodology so that necessary adjustments can be made. The pilot study was carried out at Hemato-oncology ward. This study setting was chosen because it had respondents with similar characteristics to those of main study.

Parents/caretakers for the pilot study were chosen using simple random sampling. The sample for pilot study was 10% of total sample (50) and 10% of 50 was 5. Therefore, numbers 1 to 10 were written on pieces papers and put in a box. After a vigorous shake, parents and caretakers were asked to pick one piece of paper and five parents and caretakers who picked old numbers were included in the pilot study. After the pilot study, corrections were made to the tool by removing questions that were confusing respondents on knowledge and practices. Modification of questions were done especially those that had “if no” to the question stated above then go to the next section or leave the question that followed as those restricted the participants from responding to other questions.
3.10 Ethical and cultural considerations

Ethics is a discipline dealing with principles of moral values and moral conduct (Lobiondo-Wood and Haber, 2006). Therefore, the researcher protected the respondents who were used in the study from physical or mental harm or discomfort before, during and after conducting the research.

The researcher got permission from the Senior Medical Superintendent of the University Teaching Hospital, Head of Pediatric Department and Nursing Officer for Pediatrics and the sister in charge for Hemato-oncology ward and clinic 4 for pilot and actual study respectively.

Consent was obtained from individual research respondents after the purpose of the study was explained and how findings were to be utilized. The respondents were also reassured of confidentiality concerning the data that were collected that names were not to be used instead numbers were used on the interview schedule. The respondents were told that they had the right to participate or withdraw from the study with no penalty. The completed interview schedules were kept under lock and key to avoid unauthorized access to the information contained in them.
CHAPTER 4

4.0 ANALYSIS OF DATA AND PRESENTATIONS OF FINDINGS

The purpose of the study was to determine knowledge and practices of parents/caretakers with children with sickle cell disease towards prevention of sickle cell crises at the University Teaching Hospital. Fifty respondents (parents/caretakers) who participated in the study were drawn from clinic 4 (Hematology clinic) of the University Teaching Hospital. Data was collected using an interview schedule. This chapter presents the study findings.

4.1 Data Analysis

Data analysis is the systematic organization and synthesis of research data and the testing of research hypotheses using those data (Polit et al, 2001). All interview schedules were edited for accuracy, completeness and consistence. Closed ended responses were entered in numeric form on a spreadsheet and analyzed using the Statistical Package for Social Sciences (SPSS), version 16.0. Responses from open-ended question were categorized according to similarity and then coded and finally entered on the spreadsheet. Data was then analyzed using SPSS, version 16.0.

4.2 Presentation of Findings

Data Presentation includes the description of table contents, with their data breakdowns (Statistical Data and Metadata Exchange, 2006). The study findings are presented using tables and pie charts and cross-tabulation. Presentation of findings is done according to sections beginning with section A containing demographic data, section B for social-economic data, section C containing knowledge towards prevention of sickle cell crises, section D for practices towards prevention of sickle cell crises and finally section E for social and cultural beliefs/practices towards prevention of sickle cell crises. Tables give more precise numerical information and easy understanding and interpretation of the study findings while pie charts summarize a large data set in visual form and require minimal additional explanation (Statistical Data and Metadata Exchange, 2006). All results were rounded off to the nearest one tenth using SPSS, version 16.0.
4.2.1 SECTION A: DEMOGRAPHIC DATA

This section consists of four (4) tables on demographic characteristics of the study respondents; age, marital status, number of children and number of children with sickle cell disease.

Table 4.1 Age Distribution

<table>
<thead>
<tr>
<th>Age (category) in years</th>
<th>Frequency (n=50)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-24</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td>25-29</td>
<td>8</td>
<td>16</td>
</tr>
<tr>
<td>30-34</td>
<td>14</td>
<td>28</td>
</tr>
<tr>
<td>35-39</td>
<td>11</td>
<td>22</td>
</tr>
<tr>
<td>40 and above</td>
<td>11</td>
<td>22</td>
</tr>
<tr>
<td>Total</td>
<td>50</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 4.3 shows that 14 (28%) of those interviewed fell in the age range 30-34 years. This age range was followed by those aged 35-39 and 40 and above representing 11 (22%) each while 8 (16%) were in the age range 25-29 years and the least 6 (12%) were in the age range of 20-24 years.

Table 4.2 Marital status

<table>
<thead>
<tr>
<th>Marital status</th>
<th>Frequency (n=50)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Married</td>
<td>35</td>
<td>70</td>
</tr>
<tr>
<td>Divorced</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td>Windowed</td>
<td>7</td>
<td>14</td>
</tr>
<tr>
<td>Total</td>
<td>50</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 4.4 indicates that almost three quarters 35 (70%) of those interviewed were married, 7 (14%) were widowed. Other respondents 6 (12%) were divorced and 2 (4%) were single.
Table 4.3 Number of Children

<table>
<thead>
<tr>
<th>Number of Children</th>
<th>Frequency (n=50)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-3</td>
<td>32</td>
<td>64</td>
</tr>
<tr>
<td>4-6</td>
<td>12</td>
<td>24</td>
</tr>
<tr>
<td>7-9</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>50</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Table 4.5 shows that most 32 (64%) of the respondents had children in the range of 1-3, 12 (24%) had 4-6 children while 6 (12%) had 7-9 children.

Table 4.4 Number of children with sickle cell disease

<table>
<thead>
<tr>
<th>Number of children with SCD</th>
<th>Frequency (n=50)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>45</td>
<td>90</td>
</tr>
<tr>
<td>2</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>50</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Table 4.6 shows that the majority 45 (90%) of respondents had only one child with sickle cell disease, while only 5 (10%) had 2 children with sickle cell disease.
SECTION B: SOCIO-ECONOMIC DATA

This section consists of three (3) tables on socio-economic of the study respondents; educational level, occupation and family income per month.

Table 4.5 Level of Education

<table>
<thead>
<tr>
<th>Level of Education</th>
<th>Frequency (n=50)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never been to school</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Primary school</td>
<td>17</td>
<td>34</td>
</tr>
<tr>
<td>Secondary school</td>
<td>19</td>
<td>38</td>
</tr>
<tr>
<td>Tertiary</td>
<td>12</td>
<td>24</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>50</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Table 4.7 shows that 19 (38%) of the respondents had secondary education and only 2 (4%) who never went to school.

Table 4.6 Occupation

<table>
<thead>
<tr>
<th>Occupation</th>
<th>Frequency (n=50)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self employed</td>
<td>22</td>
<td>44</td>
</tr>
<tr>
<td>Formally employed</td>
<td>14</td>
<td>28</td>
</tr>
<tr>
<td>Caregiver supporter</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Mentor-NGO</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>House wife</td>
<td>11</td>
<td>22</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>50</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

According to table 4.8, 22 (44%) of the respondents were self employed (business), 14 (28%) were in formal employment and 11 (22%) were house wives.
Table 4.7 Family income per month

<table>
<thead>
<tr>
<th>Family income per month</th>
<th>Frequency (n= 50)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>K1 000 000 and above</td>
<td>18</td>
<td>36</td>
</tr>
<tr>
<td>Between K500 000 and K999 000</td>
<td>11</td>
<td>22</td>
</tr>
<tr>
<td>Below K500 000</td>
<td>21</td>
<td>42</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>50</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Table 4.9 shows almost half 21 (42%) of the respondents had a family income of below K500 000, while 11 (22%) had an income of between K500 000 and K999 000 and 18 (36%) had income of above K1 000 000.

4.2.2 SECTION D: KNOWLEDGE ON PREVENTION SICKLE CELL CRISES

This section consists of 4 pie charts and 3 tables on knowledge questions; definition of sickle cell crisis, predisposing factors to crises, whether or not sickle cell crises are preventable, methods of preventing crises, sources of information on prevention of sickle cell crises, adequacy of information and finally level of knowledge on prevention of crises. Finally, it has 3 cross tabulations on relationships among knowledge and demographic data.
Figure 4.1 Definition of sickle cell crises

Figure 4.1 shows that almost three quarters 36 (72%) of respondents were able to define sickle cell crisis correctly that is: episodes experienced by the patient when there is a reduction of oxygen flow to the tissue precipitated by anemia, infection, dehydration or sickled blood cells block blood vessels. while the other 14 (28%) were unable to define it correctly.

Table 4.8 Predisposing factors of sickle cell crises

<table>
<thead>
<tr>
<th>Predisposing factors of crises</th>
<th>Frequency (n= 50)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infection</td>
<td>24</td>
<td>19</td>
</tr>
<tr>
<td>Exposure to cold</td>
<td>42</td>
<td>34</td>
</tr>
<tr>
<td>Fever</td>
<td>15</td>
<td>12</td>
</tr>
<tr>
<td>Doing activities demanding more oxygen</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Dehydration</td>
<td>40</td>
<td>32</td>
</tr>
</tbody>
</table>

Table 4.8 shows that the commonest known predisposing factor to sickle cell crises was exposure to cold mentioned by 42 (34%) of the respondents and the least known was doing activities demanding more oxygen.

Note: Total does not add up to 50 due to multiple responses.
Figure 4.2 Sickle cell crises are Preventable

Figure 4.2 shows that majority 41 (82%) of the respondents knew that sickle cell crises are preventable while 9 (18%) did not know whether they are preventable or not.

Table 4.9 Known preventive measures of sickle cell crises

<table>
<thead>
<tr>
<th>Methods of preventing sickle cell crises</th>
<th>Frequency (n=50)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Give plenty of fluids and fruits</td>
<td>34</td>
<td>43</td>
</tr>
<tr>
<td>Keeping child warm</td>
<td>15</td>
<td>19</td>
</tr>
<tr>
<td>Giving prescribed drugs</td>
<td>26</td>
<td>33</td>
</tr>
<tr>
<td>Giving nutritious food</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

Table 4.9 shows that the commonest known methods of preventing sickle cell crises 34 (43%) is giving plenty of fluids and fruits followed by giving the child prescribed drugs 26 (33%) and the least 5 (6%) is giving nutritious food.

Note: Total does not add up to 50 due to multiple responses.
Figure 4.3 Source of information on prevention of sickle cell crises

Figure 4.3 shows that majority 33 (66%) of the respondents got the information on prevention of crises from hospital staff, 15 (30%) from other sources while only 2 (4%) got the information from reading books.

Table 4.10 Adequacy of information given by hospital staff

<table>
<thead>
<tr>
<th>Adequacy of information</th>
<th>Frequency (n= 33)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>21</td>
<td>64</td>
</tr>
<tr>
<td>No</td>
<td>12</td>
<td>36</td>
</tr>
<tr>
<td>Total</td>
<td>33</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 4.10 shows that more than half 21 (64%) of respondents indicated that the information given by hospital staff on prevention of sickle cell crises was adequate while 12 (36%) stated that it was inadequate.
CROSS TABULATIONS ON RELATIONSHIPS AMONG KNOWLEDGE AND DEMOGRAPHIC DATA

Table 4.11 Age in relation to knowledge towards prevention of sickle cell crises

<table>
<thead>
<tr>
<th>Age</th>
<th>Knowledge on prevention of sickle cell crises</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Adequate</td>
<td>Inadequate</td>
</tr>
<tr>
<td>20-24</td>
<td>1 (17%)</td>
<td>5 (83%)</td>
</tr>
<tr>
<td>25-29</td>
<td>5 (63%)</td>
<td>3 (37%)</td>
</tr>
<tr>
<td>30-34</td>
<td>7 (50%)</td>
<td>7 (50%)</td>
</tr>
<tr>
<td>35-39</td>
<td>7 (64%)</td>
<td>4 (36%)</td>
</tr>
<tr>
<td>40 and above</td>
<td>6 (55%)</td>
<td>5 (45%)</td>
</tr>
<tr>
<td>Total</td>
<td>26 (52%)</td>
<td>24 (48%)</td>
</tr>
</tbody>
</table>

Table 4.11 shows that 7 (64%) those aged 35-39 years had adequate knowledge on prevention of sickle cell crises compared to 5 (83%) of those aged 20-24 years who had inadequate knowledge.

Table 4.12 Level of education in relation to knowledge towards prevention of sickle cell crises

<table>
<thead>
<tr>
<th>Level of education</th>
<th>Knowledge on prevention of sickle cell crises</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Adequate</td>
<td>Inadequate</td>
</tr>
<tr>
<td>Never been to school</td>
<td>0 (0%)</td>
<td>2 (100%)</td>
</tr>
<tr>
<td>Primary school</td>
<td>2 (12%)</td>
<td>15 (88%)</td>
</tr>
<tr>
<td>Secondary school</td>
<td>14 (74%)</td>
<td>5 (26%)</td>
</tr>
<tr>
<td>Tertiary</td>
<td>10 (83%)</td>
<td>2 (17%)</td>
</tr>
<tr>
<td>Total</td>
<td>26 (52%)</td>
<td>24 (48%)</td>
</tr>
</tbody>
</table>

Table 4.12 indicates that 15 (88%) of the respondents who attained primary education had inadequate knowledge towards the prevention of sickle cell crises compared to 10 (83%) of those who attained tertiary education had adequate knowledge towards prevention of sickle cell crises.
Table 4.13 Adequacy of information in relation to knowledge on prevention of sickle cell crises

<table>
<thead>
<tr>
<th>Adequacy of information</th>
<th>Knowledge on prevention of sickle cell crises</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Adequate</td>
<td>Inadequate</td>
</tr>
<tr>
<td>Yes</td>
<td>20 (95%)</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>No</td>
<td>9 (75%)</td>
<td>3 (25%)</td>
</tr>
<tr>
<td>Total</td>
<td>29 (88%)</td>
<td>4 (12%)</td>
</tr>
</tbody>
</table>

Table 4.13 shows that 20 (95%) of the respondents who said the information on prevention of sickle cell crises was adequate also had adequate knowledge on prevention of sickle cell crises compared to 9 (75%) of those who had said the information on prevention of sickle cell crises was inadequate but had adequate knowledge on prevention of sickle cell crises.

4.2.3 SECTION: D PRACTICES ON THE PREVENTION OF SICKLE CELL CRISES

Two (2) questions solicited for practices of prevention of sickle cell crises, this section has three (3) frequency tables and (4) cross tabulations on relationships among practice and demographic data.

Table 4.14 Home prevention of sickle cell crises

<table>
<thead>
<tr>
<th>Home prevention of sickle cell crises</th>
<th>Frequency (n=50)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>43</td>
<td>86</td>
</tr>
<tr>
<td>No</td>
<td>7</td>
<td>14</td>
</tr>
<tr>
<td>Total</td>
<td>50</td>
<td>100</td>
</tr>
</tbody>
</table>

The table above shows that 43 (86%) of the respondents took action to prevent sickle cell crises at home while 7 (14%) did not take any action.
Table 4.15 methods of preventing crises

<table>
<thead>
<tr>
<th>Mode of preventing sickle cell crises</th>
<th>Frequency (n=50)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Give child plenty of fluid</td>
<td>39</td>
<td>31</td>
</tr>
<tr>
<td>Feed child nutritious food</td>
<td>14</td>
<td>11</td>
</tr>
<tr>
<td>Ensure that the child sleep under a treated mosquito net</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Give prophylactic drugs</td>
<td>29</td>
<td>23</td>
</tr>
<tr>
<td>Take the child for immunization</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Dress the child in warm clothes</td>
<td>35</td>
<td>28</td>
</tr>
<tr>
<td>Restrict the child from doing exercises demanding more oxygen</td>
<td>3</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 4.15 shows that 39 (31%) of the respondents gave plenty of fluids to the child, 35 (28%) dressed their children in warm clothes, 29 (23%) gave prophylactic drugs as a way of preventing crises while only 2(2%) took the child for immunization to prevent sickle crises.

Note: Total does not add up to 50 due to multiple responses

Table 4.16 Level of practice on the prevention of crises

<table>
<thead>
<tr>
<th>Level of Practice</th>
<th>Frequency (n=50)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good</td>
<td>32</td>
<td>64</td>
</tr>
<tr>
<td>Poor</td>
<td>18</td>
<td>36</td>
</tr>
<tr>
<td>Total</td>
<td>50</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 4.16, majority 32 (64%) of respondents had good practices towards the prevention of sickle cell crises while 18 (36%) had poor practices.
CROSS TAUATIONS ON RELATIONSHIPS AMONG PRACTICE AND DEMOGRAPHIC DATA.

Table 4.17 Age in relation to practices towards prevention of crises

<table>
<thead>
<tr>
<th>Age</th>
<th>Practices on prevention of sickle cell crises</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Positive</td>
<td>Negative</td>
</tr>
<tr>
<td>20-24</td>
<td>2 (33%)</td>
<td>4 (67%)</td>
</tr>
<tr>
<td>25-29</td>
<td>6 (75%)</td>
<td>2 (25%)</td>
</tr>
<tr>
<td>30-34</td>
<td>8 (57%)</td>
<td>6 (43%)</td>
</tr>
<tr>
<td>35-39</td>
<td>8 (73%)</td>
<td>3 (27%)</td>
</tr>
<tr>
<td>40 and above</td>
<td>8 (73%)</td>
<td>3 (27%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>32 (64)</strong></td>
<td><strong>18 (36%)</strong></td>
</tr>
</tbody>
</table>

Three quarters of the respondents 6 (75%) in the age range of 25-29 years had positive practices towards prevention of sickle cell crises compared to 2 (33%) of those who were in the age range 20-24 years who had positive practices towards prevention of sickle cell crises.

Table 4.18 Level of education in relation to practices towards prevention of crises

<table>
<thead>
<tr>
<th>Level of education</th>
<th>Practices on prevention of sickle cell crises</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Positive</td>
<td>Negative</td>
</tr>
<tr>
<td>Never been to school</td>
<td>0 (0%)</td>
<td>2 (100%)</td>
</tr>
<tr>
<td>Primary school</td>
<td>6 (35%)</td>
<td>11 (65%)</td>
</tr>
<tr>
<td>Secondary school</td>
<td>16 (84%)</td>
<td>3 (16%)</td>
</tr>
<tr>
<td>Tertiary</td>
<td>10 (83%)</td>
<td>2 (17%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>32 (64%)</strong></td>
<td><strong>18 (36%)</strong></td>
</tr>
</tbody>
</table>

The above table shows that 16 (84%) of the respondents who attained secondary education had positive practices towards prevention of sickle cell crises followed by 10 (83%) who had tertiary
education while none 2 (100%) of those who never went to school had positive practices towards prevention of crises.

Table 4.19 Family income per month in relation to practices of prevention of crises

<table>
<thead>
<tr>
<th>Family income per month</th>
<th>Practices on the prevention of sickle cell crises</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Positive</td>
<td>Negative</td>
</tr>
<tr>
<td>K1 000 000 and above</td>
<td>15 (83%)</td>
<td>3 (17%)</td>
</tr>
<tr>
<td>Between K500 000 and K999 000</td>
<td>7 (64%)</td>
<td>4 (36%)</td>
</tr>
<tr>
<td>Below K500 000</td>
<td>10 (48%)</td>
<td>11 (52%)</td>
</tr>
<tr>
<td>Total</td>
<td>32 (64%)</td>
<td>18 (36%)</td>
</tr>
</tbody>
</table>

Majority 15 (83%) of those who had a family income of K1 000 000 and above had positive practices towards prevention of sickle cell crises compared to 10 (48%) of the respondents who earned below K500 000 but had positive practices towards prevention of crises.

Table 4.20 Adequacy of information in relation to practices on prevention of crises

<table>
<thead>
<tr>
<th>Adequacy of information</th>
<th>Practices on prevention of sickle cell crises</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Positive</td>
<td>Negative</td>
</tr>
<tr>
<td>Yes</td>
<td>8 (38%)</td>
<td>13 (62%)</td>
</tr>
<tr>
<td>No</td>
<td>2 (17%)</td>
<td>10 (83%)</td>
</tr>
<tr>
<td>Total</td>
<td>10 (30%)</td>
<td>23 (70%)</td>
</tr>
</tbody>
</table>

Majority 13 (62%) of respondents who said that they had adequate information on prevention of sickle cell crises had negative practices on prevention of sickle cell crises while 10 (83%) of those who said they had inadequate information on prevention of sickle cell crises also had negative practices on prevention of sickle cell crises.
4.3.4 SECTION E: SOCIAL AND CULTURAL BELIEFS/PRACTICES ON PREVENTION OF SICKLE CELL CRISIS

Three (3) questions solicited for social and cultural beliefs/practices on prevention of sickle cell crises and the section has 3 frequency tables. There are (2) cross tabulations on relationships among knowledge, practice and social cultural methods.

Table 4.21 Awareness of any negative social and cultural beliefs and practices

<table>
<thead>
<tr>
<th>Awareness of any negative social and cultural beliefs/practices</th>
<th>Frequency (n=50)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>17</td>
<td>34</td>
</tr>
<tr>
<td>No</td>
<td>33</td>
<td>66</td>
</tr>
<tr>
<td>Total</td>
<td>50</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 4.21 shows that the majority 33 (66%) of the respondents were not aware of any negative cultural practices towards the prevention of sickle cell crises while 17 (34%) said they knew some cultural practices towards prevention of sickle cell crises.

Table 4.22 Known cultural beliefs/practices towards prevention of sickle cell crises

<table>
<thead>
<tr>
<th>Known cultural beliefs/practices</th>
<th>Frequency (n=17)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use of herbs</td>
<td>14</td>
<td>82</td>
</tr>
<tr>
<td>Use of blood of rat mixed with milk</td>
<td>3</td>
<td>18</td>
</tr>
<tr>
<td>Total</td>
<td>17</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 4.22 shows that 14 (82%) of respondents knew about the use of herbs and 3 (18%) knew about the use of blood of a rat mixed with milk to prevent sickle cell crises.
Table 4.23 Ever practiced any cultural methods of preventing sickle cell crises

<table>
<thead>
<tr>
<th>Ever practiced any cultural methods of preventing SCC</th>
<th>Frequency (n=17)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>10</td>
<td>59</td>
</tr>
<tr>
<td>No</td>
<td>7</td>
<td>41</td>
</tr>
<tr>
<td>Total</td>
<td>17</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 4.23 shows that 10 (59%) of the respondents who knew some cultural practices had practiced some in preventing sickle cell crises while 7 (41%) had not practiced any.

CROSS TABULATIONS ON RELATIONSHIPS AMONG KNOWLEDGE, PRACTICE AND SOCIAL CULTURAL METHODS

Table 4.24 Ever practiced any cultural methods of preventing sickle cell crises in relation to level of knowledge towards prevention of sickle cell crises

<table>
<thead>
<tr>
<th>Ever practiced any cultural methods of preventing sickle cell crises</th>
<th>Level of Knowledge on prevention of sickle cell crises</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Adequate</td>
<td>Inadequate</td>
</tr>
<tr>
<td>Yes</td>
<td>3 (30%)</td>
<td>7 (70%)</td>
</tr>
<tr>
<td>No</td>
<td>23 (58%)</td>
<td>17 (42%)</td>
</tr>
<tr>
<td>Total</td>
<td>26 (52%)</td>
<td>24 (48%)</td>
</tr>
</tbody>
</table>

The above table shows that 7 (70%) of the respondents who had practiced cultural method towards prevention of sickle cell crises had inadequate knowledge on prevention of crises.
Table 4.25 Ever practiced any cultural methods of preventing sickle cell crises in relation to level of practices towards prevention of sickle cell crises

<table>
<thead>
<tr>
<th>Ever practiced any cultural methods of preventing sickle cell crises</th>
<th>Practices on the prevention of sickle cell crises</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Positive</td>
<td>Negative</td>
</tr>
<tr>
<td>Yes</td>
<td>3 (30%)</td>
<td>7 (70%)</td>
</tr>
<tr>
<td>No</td>
<td>29 (73%)</td>
<td>11 (27%)</td>
</tr>
<tr>
<td>Total</td>
<td>32 (64%)</td>
<td>18 (36%)</td>
</tr>
</tbody>
</table>

Table 4.25 shows that 7 (70%) of the respondents who had practiced cultural methods towards prevention of crises had negative practices on prevention of sickle cell crises.

4.2.5 RELATIONSHIPS AMONG KNOWLEDGE AND PRACTICE TOWARDS PREVENTION OF SCC

This section presents cross tabulation between knowledge and practices towards prevention of sickle cell crises.

Table 4.26 Level of knowledge in relation to practices towards prevention of sickle cell crises

<table>
<thead>
<tr>
<th>Level of knowledge on prevention of sickle cell crises</th>
<th>Practices on the prevention of sickle cell crises</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Positive</td>
<td>Negative</td>
</tr>
<tr>
<td>Adequate</td>
<td>25 (96%)</td>
<td>1 (4%)</td>
</tr>
<tr>
<td>Inadequate</td>
<td>7 (29%)</td>
<td>17 (71%)</td>
</tr>
<tr>
<td>Total</td>
<td>32 (64%)</td>
<td>18 (36%)</td>
</tr>
</tbody>
</table>

Table 4.26 shows that almost all 25 (96%) of the respondents who had adequate knowledge also had positive practices towards prevention of sickle cell crises compared to 7 (29%) of those who had inadequate knowledge but had positive practices towards prevention of crises.
4.2.6 RESPONDENTS SUGGESTIONS

Respondents’ suggestions on how to improve knowledge and practices towards prevention of crises.

<table>
<thead>
<tr>
<th>Suggestions</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital staff should always give IEC on prevention of SCC</td>
<td>31</td>
<td>86</td>
</tr>
<tr>
<td>Sickle cell crises prevention booklets should be made available for parents/caretakers to read.</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Hospital staff should have positive attitude towards parents/caretakers so that they are free to ask questions concerning crises prevention</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>Total</td>
<td><strong>36</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Majority 31 (86%) of the respondents suggested that hospital staff should always give IEC on prevention of crises, 3 (8%) suggested that hospital staff should have positive attitude towards parents/caretakers so that they are free to ask questions concerning crises prevention while 2 (6%) suggested that sickle cell crises prevention booklets should be made available for parents/caretakers to read.

Note: Total does not add up to 50 because others indicated that all was well and so they did not suggest anything.
CHAPTER FIVE
5.0 DISCUSSION OF FINDINGS AND IMPLICATIONS FOR THE HEALTH CARE SYSTEM

Chapter 5 presents discussion of findings collected from a sample of fifty (50) respondents. The respondents were parents and caretakers with children with SCD at UTH. The general objective of the study was to determine knowledge and practices of parents and caretakers with children with SCD towards prevention of sickle cell crises at Hematology clinic of UTH. The socio-demographic characteristics of the respondents which were relevant to this study were age, level of education and family income. The other variables discussed are; knowledge, practices, Information, Education and Communication and social and cultural practices on prevention of crises.

5.1 Characteristics of the sample
The sample included parents/caretakers aged 20 years and above. The majority (28%) of the respondents was between 30-34 years, 22% was between 35-39 and 40 and above years of age each respectively, 16% were between 25-29 years, 12% were between 20-24 years (table 4.1). Distribution of marital status showed that almost three quarters 70% of the respondents were married, 14% were widowed and 12% were divorced. The divorced respondents were few because divorce is not accepted socially in Zambia. Only 4% of the respondents were single (single parents) (table 4.2). Majority (64%) of the respondents had 1-3 children in the household, while 24% had 4-6 and only 12% of the respondents had 7-9 children (table 4.3). Almost all 90% of the respondents had 1 child with sickle cell disease while only 10% had 2 children with the disease (table 4.4). This could be attributed to the fact that when a couple who are positive with sickle cell trait get married, each pregnancy carries a 25% chance of having the child affected that is why those who had more than 7 children had 2 children with sickle cell disease (Muscari, 2005).

In terms of the level of education, majority 38% of the respondents attained secondary education, 34% attained primary education while 24% attained tertiary education and only 4% did not go to school (table 4.5). This is probably because Lusaka has the highest proportion of population that completed secondary education for both females and males (8 percent for females and 12 percent for males) (Central Statistic Office, 2007).
Almost half 44% of the respondents were self employed, 30% were formally employed, 22% were house wives and 4% were caregiver supporters. This could be attributed to the fact that majority of the respondents went up to secondary education followed by those with only primary education as such they could not be in formal employment.

In terms of monthly income for the family, majority (42%) of the respondents earned below K500 000, 36% earned above K1 000 000 and 22% earned between K500 000 and K999 000 (table 4.7). According to CSO, (2007), educational attainment is positively related to household wealth status. Therefore, this variation in family monthly income could be due to the findings in table 4.5 that majority (38%) attained only secondary education meaning they were not in formal employment as shown that majority (44%) of the respondents were self employed (table 4.6). This could have influenced family income depending on the type of business one does.

5.2 Discussion of Variables

5.2.1 Knowledge on prevention of sickle cell crises

Knowledge is the information that a parent and caretaker have on the prevention of sickle cell crises. Therefore, knowledge about the cause, impact and prevention is critical in the management of sickle cell disease. Almost three quarters (72%) of the respondents were able to define sickle cell crisis correctly while 28% defined it wrongly (figure 4.1). The correct definition given was episodes experienced by the patient when there is a reduction of oxygen flow to the tissue precipitated by anemia, infection, dehydration or sickled blood cells block blood vessels. This was followed by another question which was asked to establish whether parents/caretakers knew some of the predisposing factors to sickle cell crises. The findings showed that the commonest known predisposing factors to sickle cell crises were exposure to cold mentioned by 34% of respondents followed by dehydration 32% and infection 19%. Fever and doing activities demanding more oxygen were the least known predisposing factors with 12% and 3% responses respectively.

These results are similar to the findings of Jaffer et al, (2009) which established that cold, fever, exhaustion, vomiting and diarrhea were among the leading predisposing factors to sickle cell crises.

According to the National Heart, Lung and Blood Institute of NIH, (2007), on Management and Therapy of Sickle Cell Disease, there is no cure for sickle cell disease but crises can be prevented by
employing preventive measures such as maintaining adequate nutrition to optimize the patient’s resistance to infection and resources for healing. In this study, the commonest known methods of preventing sickle cell crises was giving plenty of fluid and fruits as stated by 43% of the respondents. The second commonest known method was giving prescribed drugs mentioned by 33% and 19% were keeping the child warm. The least known method of preventing sickle cell crises was giving nutritious food (6%), yet this method is very vital to children with SCD as it improves and boosts the child’s immunity thus reducing the chances of getting infections consequently crises.

Regarding parents and caretakers’ source of information on prevention of sickle cell crises, majority 66% got information from hospital staff while 30% got from other parents and caretakers who have children with sickle cell disease and the least 4% from reading books (Figure 4.3).

Concerning adequacy of information given, table 4.10 indicates that among the respondents who received information from hospital staff, 64% stated that information on prevention of sickle cell crises was adequate while 36% stated that it was inadequate. This is probably because each time the parent/caretaker took the child to clinic for review or when admitted to hospital, hospital staff gave them information on prevention of crises. These results are in line with those of Milosavljevic et al, (2007) on ‘Sickle cell disease; Experience of the caregivers in managing the disease in children living in the Western Region of Jamaica’ where caregivers indicated that they knew the basic facts about the disease and how to manage unwanted complications at home because they were given clear information by doctors and nurses each time they visited the clinic. With such a system in place, caretakers are expected to have adequate knowledge about the disease and how to manage and prevent crises at home. Therefore, giving correct and adequate information on the management of SCD to parents/caretakers is significant in enhancing their knowledge on prevention of crises.

The study findings on age in relation to knowledge revealed that older parents and caretakers had adequate knowledge on prevention of crises compared to younger parents and caretakers (Table 4.11). Majority (83%) of respondents who were aged 20-24 years as the youngest had inadequate knowledge on prevention of crises compared to 45% of the oldest aged 40 years and above who had inadequate knowledge. These results are supported by the research conducted by Arrayed and Hajeri, (2009), on ‘Public awareness of sickle cell disease in Bahrain’ which showed respondents who were 60 years and older gave more correct answers and those who had previously heard of SCD answered
34 items (94%) correctly. This means that older parents and caretakers are more experienced and knowledgeable about sickle cell disease and prevention of crises while younger ones lack experience.

The findings on the level of knowledge in relation to practice towards prevention of crises showed a relationship between the two because according to table 4.26, majority (96%) of the respondents who had adequate knowledge also had positive practices towards prevention of crises compared to 29% of those who had inadequate knowledge but had positive practices. The level of knowledge of parent and caretaker helps to understand the information being given during IEC and in turn would influence her/his practices towards prevention of crises.

5.2.2 Practices on prevention of sickle cell crises

Practice is the actual steps a parent or caretaker takes to prevent sickle cell crises. In this study, majority 86% of the respondents indicated that they took action to prevent crises at home while 14% did not take any action (Table 4.14). This could be due to the fact that 52% of the respondents had adequate knowledge on prevention of crises which could have influenced their practices (figure 4.4). To prevent crises, 31% of the respondents gave their children plenty of fluid while 28% dressed their children in warm clothes and 23% gave prophylactic drugs. Others (11%) fed their children with nutritious food, 3% ensured that their children slept under a treated mosquito net, restricted their children from doing exercises demanding more oxygen and taking children for immunization were 2% each respectively (Table 4.15). Jaffer et al (2009) stated that all modes of preventing precipitating factors to sickle cell crises are good practices and parents and caretakers should adhere to them as they are cheap.

Overall, most 64% of the respondents had positive practices towards prevention of sickle cell crises (table 4.16). These positive practices would have been as a result of adequate knowledge 96% that parents and caretakers had compared to 29% of respondents who had inadequate knowledge but had positive practices towards prevention of crises (table 4.26). This meant that they understood the importance of preventing crises and the consequences of crises. Therefore, we fail to reject the hypothesis stating that the more knowledge parents and caretakers have concerning preventive measures, the more likely that they will have good practices towards the prevention of crises.
Respondents’ level of education had an impact on the level of practice towards prevention of sickle cell crises. Those who went up to secondary and tertiary education (84% and 83%) as shown in table 4.18 had positive practices towards prevention of crises compared to those who never went to school. According to CSO (2007), educational attainment has a strong effect on health behaviors and attitudes of an individual. Educational attainment influences level of knowledge and consequently influences practices towards prevention of crises. This is because parents and caretakers with high level of education understand the consequences of frequent attacks of crises. Similarly, Arrayed and Hajeri (2009) as stated earlier, indicated that professionals showed a significantly good level of knowledge about the nature of SCD, the different types of SCD, how it is diagnosed, and the prevalence of the disease, the inheritance pattern, the symptoms, and the management. The study further stated that University students answered 9 of 38 items (24%) correctly, which was significantly better than the performance of respondents with lower level of education (illiterate). Therefore, we fail to reject the hypothesis stating that the higher the level of education of a parent and caretaker, the more likely she/he will have adequate knowledge and good practices towards prevention of crises.

5.2.3 Economic status of parents/caretakers towards prevention of sickle cell crises
Family monthly income of parents/caretakers was measured to establish if it influenced parents and caretakers’ practices on prevention of sickle cell crises. Table 4.19 shows that 83% of the respondents who had a monthly income of K1 000 000 and above had positive practices compared to 48% of those who earned below K500 000 and had positive practices towards prevention of sickle cell crises. This is probably because families with high income were able to buy nutritious food needed for their children, warm clothes and also accessed health services easily where they may be given information on prevention of crises. This fails to reject the hypothesis that the higher income status of a family, the higher the knowledge and positive practices towards prevention of sickle cell crises.

Kofi et al. (2010), stated that people who are illiterate and poor are subjected to economic exploitation, deprivation which is reflected in their low quality of life. These occupy the lowest step of the social ladder, leading to inability to meet the daily demands of their sickle cell afflicted children. In another related research conducted by Milosavljevic et al (2007), indicated that
caregivers interviewed stated that those who held some kind of a job and health insurance were able to buy prescribed drugs, pay for transport and pay hospital bills while mothers with low income salaries were faced with big problem if there were prescribed drugs to buy. Similarly, Muscari, (2005) indicated that low socio-economic status had an adverse influence on health and this may be due to escalating health care costs, eating unbalanced and insufficient food, no health visits due to lack of funds, inadequate housing that result in overcrowding, poor sanitation and greater chance to expose to communicable diseases. Further, perceived barrier of Health Belief Model also indicates that financial limitation can be a barrier to practice preventive measures of crises as parents/caretakers would not be able to meet the daily requirement of sicklers. It is for this reason that most (52%) of the parents and caretakers who earned below K 500 000 had negative practices towards prevention of crises.

5.2.4 Information, Education and Communication on prevention of sickle sell crises

All the respondents who never went to school had inadequate knowledge towards prevention of sickle cell crises compared to 17% who attained tertiary education (table 18). The level of education of parents/caretakers helps to grasp information being given during health education and in turn this would influence their practices towards prevention of sickle cell crises. Table 4.18, shows that 84% of the respondents who attained secondary education had positive practices towards prevention of crises compared to none of those who did not go to school. This is because there level of education facilitated their understanding of information that was being given to them by hospital staff on prevention of crises.

Almost all (95%) of the respondents who indicated that information given by hospital staff on prevention of crises was adequate also had adequate knowledge on prevention of crises (Table 4.13). In this context IEC is given to increase parents and caretakers’ knowledge and to promote positive practices towards prevention of crises. Similarly, in study that was conducted by Bulgir (2010), entitled Intervention and Prevention of Hereditary Hemolytic disorder; an experience from KAP studies indicated that in a pre intervention, all the respondents did not know about SCC and precaution to take to prevent them but after the intervention (IEC) 83.6% were able to explain what SCD, sickling and precaution to take to prevent them. Self-efficacy of the Health belief Model
indicates that change in parents and caretakers can only come if correct information regarding the disease and its consequences are given and this can be achieved through constant health education.

More than half 62% of the respondents who indicated that information given was adequate had negative practices towards prevention of crises (table 4.20). In this case parents and caretakers’ practices are influenced by other factors other than information such as family monthly income, level of education, beliefs, attitude and age other than having adequate knowledge alone. The findings reject the hypothesis stating that the more Information, Education and Communication given to parents and caretakers concerning preventive measures, the more likely that they will have positive practices towards the prevention of sickle cell crises.

5.2.5 Social and cultural practices on prevention of sickle cell crises
Concerning awareness of any negative social and cultural practices on prevention of sickle cell crises, the study revealed that 34% of the respondents knew some social and cultural practices towards prevention of crises while 66% did not know of any (Table 4.21). The commonest social and cultural beliefs/practices towards prevention of sickle cell crises were use of herbs 82% and use of blood of a rat mixed with milk 18% (Table 4.22). Slightly above half 59% of the respondents practiced these cultural beliefs/practices while 41% did not (Table 4.23). Those who practiced cultural practices also had inadequate knowledge (70%) which could have attributed to the use of those none medically recommended practices (Table 4.24).

According to Muscari, 2005, cultural beliefs have an influence on health/illness and on the quality of life. This means that some family may rather use folk healers believing that they are more powerful. Erinosho, (2005) also explains that the general belief among people is that illness can be caused by natural, preternatural and mystical factors. The preternatural explanation is related to the belief in witchcraft where the onset of illness is attributed to the evil machinations of an enemy and he concluded that in most cultures, there is the belief that a sorcerer, wizard and other malevolent human beings can cause illnesses, including sickle cell disease. Where there is no sound knowledge about the causes, impacts and prevention of sickle cell disease, then the preternatural and mystical beliefs will be predominant and this will definitely affect people’s practices towards prevention of crises. Himaubi, (2004) stated that if parents and caretakers believe that their children have been bewitched, they will not comply with medical advice as a result they will always use traditional medicine.
Similarly this is built from the Health Belief Model of perceived barrier which states that misconception about the disease being caused or associated with witchcraft can be a barrier to parents and caretakers to practice medically recommended preventive measures of crises. Similarly, this study revealed that 70% of those who had practiced some cultural beliefs/practices towards prevention of crises also scored very low on practices towards prevention of crises. These points out that social-cultural belief have influence on the knowledge and practices of parents and caretakers on prevention of crises.
5.3 Significance to Nursing

5.3.1 Nursing Practice
The study revealed that 66% of the respondents got information on prevention of SCC from hospital staff while 34% got from other sources. However, more than half 62% of the respondents who indicated that information given by hospital staff was adequate had negative practices towards prevention of crises (table 4.20). Majority 83% of the respondents who indicated that they had inadequate information on prevention of crises also had negative practices (table 4.20). Therefore, in order to enhance parents and caretakers’ practices towards prevention of crises, hospital staff need to demonstrate the actual practices in addition to giving IEC. This would be of help to parents and caretakers because it is easy to put observed behavior into practice. There is also need for hospital staff to ensure that all parents and caretakers are given IEC on prevention of crises on each visit to hospital/clinic as information given by hospital staff is more valid and reliable than from other sources.

5.3.2 Nursing Education
The study findings show that 48% of the respondents had inadequate level of knowledge on prevention of sickle cell crises (figure 4.4), and 71% of those who had inadequate level of knowledge also had negative practices towards prevention of sickle cell crises (table 4.26). Therefore, this calls for nurse educators to equip nurses with adequate knowledge on SCD and methods of preventing sickle cell crises and in turn these nurses will be able to pass on the information to parents and caretakers.

5.3.3 Nursing Administration
The study has revealed that 66% of the respondents got the information on prevention of sickle cell crises from hospital staff while 34% got from other sources (Figure 4.3). Almost half 48% of the respondents had inadequate knowledge on prevention of crises. This could be due shortage of nurses affecting the time they spend in educating and the quality of information given to these parents and caretakers. Lack of health educational materials may also lead to poor delivery of health education to parents and caretakers. Therefore, there is need for a nurse manager to ensure that there are adequate staffing levels by lobbying for more nurses. This will enable them have spend much of their time
educating parents and caretakers thus improve their knowledge and consequently their practices towards prevention of sickle cell crises. Nurse Manager should closely supervise junior nurses to ensure correct health information on prevention of sickle cell crises is given to parents and caretakers. Nurse Manager should also ensure that health educational materials are made available and adequate to enable the nurses give information to parents and caretakers as some parents and caretakers learn well with the help of visual aids such as posters, diagrams etc.

5.3.4 Nursing Research
There are no studies that have been done determining knowledge and practices of parents and caretakers with children with SCD towards prevention of SCC in Zambia. In addition, the sample (50) was too small to represent the majority of the parents/caretakers and it was a quantitative study where answers were predetermined and therefore, limits generalization of the study findings.

It is important that similar researches are conducted on a larger scale so that the results can be generalized and in the same vain a qualitative study can be conducted to allow parents and caretakers to freely discuss their views than quantitative one. Further researches can be conducted to determine Parental Attitude to Children with Sickle Cell Disease and also to determine people's Knowledge and Attitudes towards Sickle Cell Disease Screening. This will help determine how much information people have concerning SCD and also help them make an informed decision on whether to have children or not.

5.4 Conclusion
This study was conducted to determine knowledge and practices of parents/caretakers with children with sickle cell disease towards prevention of sickle cell crises at hematology clinic of the University Teaching Hospital. The researcher sought permission from relevant authorities from UTH and fifty (50) respondents were selected using the simple random sampling method. Interview schedule was used to collect data. Data was analyzed using SPSS, version 16.0.

The study revealed that 52% of the respondents had adequate knowledge on prevention of sickle cell crises. Further analysis revealed that majority (64%) of the respondents had positive practices towards prevention of crises. It was observed that 83% of the respondents who had a high family income defined as K1 000 000 and above had positive practices towards prevention of sickle cell
crises as compared to 48% of the respondents who earned below K500 000 but had positive practices. Respondents who went up to secondary and tertiary level of education (84% and 83%) respectively had positive practices towards prevention of crises while all (100%) those who never went to school had negative practices. The study further revealed that 70% of the respondents who practiced cultural methods towards prevention of crises had inadequate knowledge compared to 30% who practiced cultural methods but had adequate knowledge. The study revealed that there is relationship between knowledge, economic status of the family, level of education of parents and caretakers and positive practices towards prevention of crises.

Therefore, the link between parents and caretakers’ knowledge and practices was uncovered suggesting the importance of continuing giving health education to parents/caretakers on crises prevention so as to enhance their practices. Consequences of SCD crises will be prevented if parents/caretakers become aware and adherent to the preventive measures of SCD crises.

5.5 Recommendation

The following recommendations are based on the findings of this study:

To Ministry of Health

- The Ministry should ensure that sickle cell crises prevention booklets are made available to hospitals for parents and caretakers to be reading in order to keep on reminding themselves on prevention of crises.
- The Ministry of Health should support Sickle Cell Association financially and materially to enable the association disseminate information on sickle cell disease and its consequences to the people affected in the community thus improves their knowledge and practices towards prevention of sickle cell crises.
- Ministry of Health should also continue funding nursing schools in order to train more nurses and in turn this will improve the staffing levels in the hospitals. This will enable staff spend time reminding parents and caretakers through health education on each visit to the clinic on the importance and benefit of preventing crises.
To University Teaching Hospital Management

- University Teaching Hospital Management should encourage hospital staff need to demonstrate the actual practices in addition to giving IEC on prevention of crises as this would be of help to parents and caretakers because it is easy to put observed behavior into practice.

- There is also need for hospital staff to ensure that all parents/caretakers are given IEC on prevention of crises on each visit to hospital/clinic as information given by hospital staff is more valid and reliable than from other sources.

- The Hospital Management should work in collaboration with Sickle Cell Association of Zambia in order to promote behavior change in prevention of sickle cell crises.

- The Hospital Management should ensure that SCC prevention booklets are available and put where parents/caretakers will be able to access them.

5.6 Dissemination of findings

A number of copies will be printed and disseminated to the following departments:

- The Department of Nursing Science of the University of Zambia to be used by the incoming students who would like to undertake similar studies as reference material.

- The University of Zambia, School of Medicine Library for literature review for other students.

- The Ministry of Health who sponsored the project to use it for formulating of protocols on prevention of sickle cell crises.

Other departments include the University Teaching Hospital and SCD Association of Zambia will be availed with the study findings as they are all interested in finding ways of continuous improving the knowledge and practices of parents and caretakers towards prevention of crises. The researcher also intends to publish the research findings in one of the local journals for others to use as reference.

5.7 Limitation of the Study

- The study comprised of parents/caretakers from UTH thus results might not be generalized to other hospitals in Zambia and the sample (50) was too small to represent the majority of the parents and caretakers. This also limits generalization of the study findings.
• Funding of the study project was not adequate to meet the cost of the study as a result the researcher failed to employ an assistant to help in data collection.

• Literature used in this study did not address sickle cell crises prevention in children instead those used were articles on knowledge, awareness and attitude towards SCD prevention in general and conducted elsewhere outside Zambia. Therefore, it was difficult to compare the results of this study.
REFERENCES


THE UNIVERSITY OF ZAMBIA

SCHOOL OF MEDICINE

INTERVIEW SCHEDULE

TITLE: KNOWLEDGE AND PRACTICES OF PARENTS/CARETAKERS WITH CHILDREN WITH SICKLE CELL DISEASE TOWARDS PREVENTION OF SICKLE CELL CRISIS AT UTH.

DATE OF INTERVIEW..............................

LOCATION OF INTERVIEW.........................

NAME OF INTERVIEWER............................

INSTRUCTIONS TO THE INTERVIEWER

1. Introduce yourself to the respondent.
2. Explain the purpose of the interview and what the study is about.
3. Ask for permission to interview and assure the respondent that all responses will be treated confidentially.
4. Individual names and address should not appear on the interview schedule.
5. Ensure that all questions are answered and indicate responses by ticking in the appropriate box or filling in the spaces provided.
6. Always use a pencil for writing or ticking (✓).
7. Keep all the information collected confidential.
8. Thank the respondent at the end of each interview.
SECTION A

Biodemographic Data

1. How old were you on your last birthday?
   a. 15 - 19 Yrs [ ]
   b. 20 - 24 Yrs [ ]
   c. 25 - 29 Yrs [ ]
   d. 30 - 34 Yrs [ ]
   e. 35 - 39 Yrs [ ]
   f. 40 and above [ ]

2. What is your marital status?
   a. Single [ ]
   b. Married [ ]
   c. Divorced [ ]
   d. Widowed [ ]
   e. Separated [ ]

3. How many children do you have? ..............................................

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

SECTION B

Socio-Economic Data

5. What is your educational level?
   a. Never been to school [ ]
   b. Primary School [ ]
   c. Secondary School [ ]
   d. College [ ]
   e. University [ ]
6. Are you in formal employment?
   a. Yes [ ]
   b. No [ ]

7. What is your occupation?
   .................................................................

8. How much is your family income per month?
   a. Above K1,000,000.00 [ ]
   b. Between K500,000 and K999,000.00 [ ]
   c. Below K500,000.00 [ ]

9. Is your income adequate to take care of your SCD child at home?
   a. Yes [ ]
   b. No [ ]

SECTION C

Knowledge of parents/Caretakers with Children Sickle

Cell Disease on the Prevention of Sickle Cell Crises

10. What is sickle cell disease? (In your own words)
    .................................................................
    .................................................................
    .................................................................

11. What is sickle cell crisis? (In your own words)
    .................................................................
    .................................................................
    .................................................................
12. Are sickle cell crises preventable?
   a. Yes [ ]
   b. No [ ]

13. If yes to question 11, how do you prevent crises?
   ..............................................................
   ..............................................................
   ..............................................................

14. What are predisposing factors to sickle cell crises?
   ( Tick all correct answers).
   a. Infection [ ]
   b. Exposure to cold [ ]
   c. Fever [ ]
   d. Doing activities demanding more oxygen [ ]
   e. Sleeping under mosquito net [ ]
   f. Dehydration [ ]

15. What is the source of your information on sickle cell crises prevention?
   a. Hospital staff
   b. Books
   c. Internet
   d. Others specify.........................

16. If the source of your information was from the hospital staff, was the information adequate?
   a. Yes [ ]
   b. No [ ]
SECTION D

17. Do you prevent sickle cell crises before the child goes into a crisis?
   a. Yes [ ]
   b. No [ ]

18. How do you prevent sickle cell crises?
   (Tick all correct answers)
   a. Give child plenty of fluids [ ]
   b. Feed child nutritious food [ ]
   c. Ensure that the child sleep under a mosquito net [ ]
   d. Give prophylactic drugs [ ]
   e. Take child to traditional healer [ ]
   f. Dress the child warm clothes [ ]
   g. Restrict the child from doing exercise demanding more oxygen [ ]
SECTION E

Social and Cultural Practices of Parents/Caretakers with

Children with Sickle Cell Disease on the prevention of Sickle

Cell Crises

19. Are there any social and cultural practices towards
   prevention of sickle cell crises which you know?
   a. Yes
      [ ]
   b. No
      [ ]

20. If yes to question 20, what are some of these practices?
   ..................................................................................
   ..................................................................................
   ..................................................................................

21. Do you practice some of the social and cultural practices
    mentioned in question 21?
   a. Yes
      [ ]
   b. No
      [ ]

22. What recommendations/suggestions can you give on
    how knowledge and practices towards prevention of sickle cell
    crises among children with sickle cell disease can be improved.
   ..................................................................................
   ..................................................................................
   ..................................................................................

END OF INTERVIEW

THANK YOU!
APPENDIX V

The University of Zambia
Department of Nursing Sciences
School of Medicine
P.O Box 50110
LUSAKA
12th October, 2011

The Medical Superintendent
University Teaching Hospital
RW 1x
LUSAKA

UFS: The Head,
Department of Nursing Sciences
University of Zambia
School of Medicine
Box 50110
LUSAKA

Dear Sir/Madam

RE: PERMISSION TO CARRY OUT A RESEARCH STUDY

I am a 4th year student at the University of Zambia, School of Medicine in the Department of Nursing Sciences pursuing a degree in Nursing.

In partial fulfillment of this programme, I am required to conduct a Research study. The title of my study is “Knowledge and practices of parents/caretakers with children with sickle cell disease towards prevention of sickle Cell Crises at the University Teaching Hospital”. I therefore, write to request for permission to carry out this study at Sickle Cell Disease (Hematology) Clinic 4 of the University Teaching Hospital. I intend to conduct this exercise between 21/10/2011- 11/11/2011.

 Yours faithfully

Hamulandabala Hilda
The Medical Superintendent  
University Teaching Hospital  
RW 1x  
LUSAKA

UFS: The Head,  
Department of Nursing Sciences  
University of Zambia  
School of Medicine  
Box 50110  
LUSAKA

Dear Sir/Madam

RE: PERMISSION TO CARRY OUT THE PILOT STUDY

I am a 4th year student at the University of Zambia, School of Medicine in the Department of Nursing Sciences pursuing a degree in Nursing.

In partial fulfillment of this programme, I am required to conduct a Research study. The title of my study is "Knowledge and practices of parents/caretakers with children with sickle cell disease towards prevention of sickle Cell Crises at the University Teaching Hospital". I therefore, write to request for permission to carry out pilot study at Hemato-oncology ward of the University Teaching Hospital. I intend to conduct this exercise between 15-20th October, 2011.

Yours faithfully

Hamulandabala Hilda
The Medical Superintendent  
University Teaching Hospital  
RW 1x  
LUSAKA

UFS: The Head,  
Department of Nursing Sciences  
University of Zambia  
School of Medicine  
Box 50110  
LUSAKA

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Yours faithfully

Hamulandabala Hilda
## APPENDIX II

### WORK PLAN FROM JUNE, 2011 TO APRIL, 2012

<table>
<thead>
<tr>
<th>Task to be performed</th>
<th>Responsible person</th>
<th>Dates</th>
<th>Time required</th>
</tr>
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<td>Continuous</td>
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**BE PERFORMED FROM JUNE 2011 TO APRIL 2012**

**THE CANTT CHART SHOWING VARIOUS TASKS TO BE UNDERTAKEN AND THE TIME REQUIRED FOR EACH TASK TO**

**APPENDIX III**
APPENDIX IV

BUDGET

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APPENDIX VI

Budget Justification

Stationery

To conduct the study effectively and professionally, stationery will be needed such as realm of papers for printing questionnaires and research proposal. Ball pens, pencils for writing notes, typex for erasing mistakes, a research bag for carrying questionnaires during data collection, stapler for stepping documents. A notebook will also be needed for record keeping during data collection and analysis. The scientific calculator will be required for data analysis.

Secretarial services

Funds for typing work will be required to pay a hired secretary, photocopying, printing and binding of final documents so that the findings are presented and to keep the information safe will be required.

Personnel

The researcher will need transport money to easy movements to and from the areas of data collection. There will be need for lunch allowances during the data collection period because of long stay in the field.

Contingency fund

10% of the total budget (contingency fund) will be required in case of any unforeseen circumstances during the period of research.