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Knowledge, Attitudes and Practices of Caregivers of Children with Sickle Cell Disease Towards Sickle Cell Disease At Kitwe Teaching Hospital, Kitwe Zambia

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Abstract

Introduction: Sickle cell disease is a genetic autosomal recessive disease that causes considerable morbidity and mortality and affects millions of people globally. The WHO has advocated for SCD awareness, however, studies on the impact of these awareness programmes through knowledge, attitudes and practices assessment among caregivers has rarely been studied. Zambia lacks resources to support the increasing incidences of the disease, hence the need to find innovative ways to prevent complications of SCD, one of them being educating care givers on home based prevention of sickle cell crises. The objective of this research was to evaluate the knowledge, attitude and practices of caregivers of children with SCD towards SCD at Kitwe teaching hospital in Kitwe, Zambia.

Methodology: A cross sectional study was conducted on caregivers of children with SCD at Kitwe teaching hospital in Kitwe with a targeted sample size of 227 participants. Non probability sampling techniques was employed while self-administered questionnaires and interviews were used to collect data. Data was analyzed using SPSS version 22.0.

Results: A total of 192 (84.58%) respondents were included in the final analysis. Majority (65.6%) of the participants had good knowledge, 83.3% had a positive attitude towards prevention of sickle cell crises while 84.4% engaged in good practices to reduce frequency of SCC. Factors that influenced the level of knowledge included age, level of education, monthly income and social cultural practices as these were statistically significant ($p<0.05$).

Conclusion: The study reviewed that respondents had good knowledge about SCD and prevention of SCC. Majority had positive attitudes and good practices towards prevention of SCC. However, some caregivers are still lacking in knowledge, attitudes and practice towards SCD.

Keywords: Arthur Davidson Children Hospital (ADH) • Sickle cell • Prevalent • Genetic • Preventing

Abbreviations: ADH: Arthur Davidson Children Hospital; KTH: Kitwe Teaching Hospital; KAP: Knowledge, Attitudes and Practices; IEC: IEC: Information Education Communication; MoH: Ministry of Health; SCA: Sickle cell Anemia; SCC: Sickle Cell Crises; SCD: Sickle Cell Disease; SCT: Sickle Cell Trait; UTH: University Teaching Hospital; USA: United States of America; WHO: World Health Organization

Introduction

Background

Sickle Cell Disease (SCD) is one of most costly and prevalent genetic disorder affecting 200-25 million people globally and has been recognised as a public health concern by the United Nations general assembly due to the morbidity, mortality and the significant social and economic impact caused by the disease [1]. SCD is an autosomal recessive hemoglobinopathy characterized by the point mutation of the β globin in the genome sequence resulting in mutational replacement of valine for glutamic acid at the sixth position of the β chain of hemoglobin [2]. Historically, the disease dates as far as 1910 when James B. Herick noticed peculiar elongated and sickle shaped red blood cells in a case of severe

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anaemia, Linus Pauling on the other hand demonstrated electrophoretically an abnormal haemoglobin S which is an abnormal variant of haemoglobin A in 1949 [3]. A sickle cell patient is one who inherited two abnormal genes that code for hemoglobin S instead of hemoglobin A and this possess serious health problems as patients tends to have attacks called crises (aplastic, hemolytic, sequestration and vaso-occlusive) as the red blood cells sickle when the body is subjected to conditions like infections, dehydration, physical exercise, extreme temperatures and other forms of stress [4].

Globally, 300,000 babies are born with SCD annually with the greatest burden existing in Sub-Saharan Africa where 75% of the world SCD occurs, predominantly in West and Central Africa and 50-80% of infants born with SCD in Africa die before the age of 5 years [5]. SCD has been an invisible global health issue, especially in regions of high incidence due to lack of awareness among laocal health policy makers and the public. About half of the children with SCD in Africa will not live past the age of 5 years old and 20% in India will not live past the age of 3 years [6]. Unfortunately, most children in these regions lack the most basic healthcare. The focus for many of these countries is disease awareness, screening, and access to care [7].

In Zambia, sickle cell trait is carried by 20%-25% of the population, 1%-2% of babies born with the disease, UTH and ADH has more than 16,000 active SCD patients and majority are <15 years. Additionally, 10% of the total admissions to the ADH are due to SCD [8]. Being a developing nation, resources to support the increased incidence of the disease are not readily available thereby increasing the need for innovative ways of preventing complications that may arise secondary to the disease. One of the ways being finding out how knowledgeable caregivers of SCD patients are with regards to basics of the disease and factors that precipitate sickle cell crises which is a form of secondary prevention of the disease. 83% of caregivers to SCD patients at UTH had low level of knowledge about SCD, this was attributed to low educational level, not being counselled on SCD or receiving educational materials regarding SCD such as books, pamphlets or videos as the main source of information they had was from the health workers [9].

Ministry of health introduced SCD screening of new borns at ADH, recommended IEC at the time of diagnosis and subsequent hospital visit to caregivers and patients and other public health awareness programmes on SCD. However, assessment of the effectiveness of these interventions has been lacking. Therefore, this project helped to evaluate the knowledge, attitudes and practices of caregivers of children with SCD towards SCD at KTH in KITWE ZAMBIA.

Statement of the problem

In Zambia, 20%-25% of population carries the sickle cell trait and 1%-2% of babies are born with the disease [10]. Zambia lacks resources to support the increasing incidences of the SCD, hence the need to find innovative ways to prevent complications of SCD, one of them being educating care givers on home based prevention of sickle cell crises and disease management. A study at ADH in Ndola showed that 16.7% of parents of children suffering from SCD had poor knowledge about SCD, 44.9% had average knowledge while 18.5% had good knowledge. There is no information on how health education sessions to caregivers increase their level of knowledge and adherence to recommended preventative interventions at Kitwe teaching hospital. Therefore, this study helped to evaluate the knowledge, attitudes and practices of caregivers of children with SCD towards SCD.

Rationale

This research provided quantitative information on the level of knowledge, described the attitudes and what practices caregivers of children with SCD engaged in as preventative interventions of complications that may arise due to the disease. Further, it highlighted factors that influence the level of knowledge and practices of caregivers of the affected children. Additionally, the project gave a general picture of the impact and effectiveness of the already existing modes of information dissemination to the caregivers. Lastly, the information can be used by the state, civil society and general public to implement measures that will help and improve the well-being of every child suffering from SCD with regards to home based healthy practices offered by caregivers as recommended by ministry of health.

Global review

SCD is a growing global health problem. The disease is most common in sub-Saharan Africa, Mediterranean basin, Middle East, and India. Because of slave trading and contemporary population movements, the distribution of SCD has spread far beyond its origins and approximately 100,000 persons have SCD in the United States occurring 1 out of every 365 African-American births while 1 in 13 African-American babies is born with SCT [11]. There are 14,000 people living with SCD in the UK and 270 babies are born with SCD each year [12].

According to Jaffer, et al. knowledge about SCD and precipitating factors of sickle cell crises affect attitude, hence caregiver's knowledge regarding sickle crises preventive measures is correlated with their attitude toward preventive practices. A study in the UK among SCD adult patients noted that knowledge of SCD among healthcare workers in an emergency setting was inadequate compared to those in planned care settings, like a hospital ward or a specialty clinic. With planned care, 76% of patients reported being treated by people who had sufficient knowledge about their disease, however in an emergency care setting only 45% of respondents felt the same [13]. There are still knowledge gaps regarding SCD among health workers who are a major source of information on SCD, this simply shows the need to know the knowledge levels in the recipients who are the caregivers to SCD patients.

Six months to five years of age is the period in which children are mostly affected as first sickle cell crisis usually appears around this time, hence the need for education about the nature of the disease and recognition the earliest signs of crises by the caregivers. In India, a study on the impact of education on the knowledge and skills of parents of children with SCD showed that 37% knew what sickle cell anaemia is while 63% responded incorrectly. Post education test scores regarding the knowledge improved significantly. All parents were now aware about SCD and 86.66% had detailed knowledge about it [14].

Another study on KAP's about SCA in patients with positive sickle cell status in Bardoli Taluka, India showed that only 16% of the study participants had correct knowledge of the symptoms of SCA and females were more active as compared to males in taking medication for SCA. To add on, 90% didn't know the cause of disease and only 18% were given information about this disease.

Saudi Arabia has Up to 27% of the population having the trait, with 2.6%-4.2% manifesting as SCD because of high occurrence of consanguinity between first cousins (>50% of total marriages) and the population's lack of awareness of inherited hematological diseases. A cross-sectional KAP study conducted at King Khalid university hospital in Saudi Arabia showed 28.8% of participants had good knowledge about SCD, 71.2% had poor knowledge while 21.4% and 14.8% participants were aware of its treatment limitations and inheritance pattern, respectively. Additionally, 41% had good attitude while 59% had poor attitude toward premarital screening. Lastly, only 19.1% had good practice while the remaining 80.9% had poor practice toward premarital screening [15].

Regional review

Africa has the highest prevalence of SCD with over 75% of the global burden residing in sub-Sahara Africa and an estimated 200,000 babies born with the disease annually. As a result of limited access to early diagnosis and comprehensive SCD care, Sub Saharan Africa accounts for 50% to 90% of the SCD related mortality in children under the age of five years.

Research carried out among caregivers of children with SCD at Mnazi mmoja hospital in Tazania showed that 53.3% of caregiver's had inadequate knowledge on SCD and its related complications, *i.e* they were unable to describe SCD as a disease of red blood cells, unaware that it is inheritable and could not mention the common related complications. To add on, 52% of the caregivers had inappropriate home based care practices for prevention of SCD complications such as not taking penicillin prophylaxis regularly and not sleeping under insecticide treated mosquito nets for prevention of malaria. Lastly, 89% of the enrolled children were reported to have at least one complication in the past 6 months and 55.8% of caregiver' to these children had inadequate SCD knowledge while 54.7% had inappropriate practices. It is evident that inadequate caregivers' knowledge on disease related complications and home based care practices negatively affect the overall wellbeing of children with SCD.

A community study conducted in Uganda which has the 5th highest disease burden in Africa as 15 000 babies are born with SCD each year reviewed that 91.2% of the respondents heard of SCD with the highest proportion 38.7% hearing of SCD from friends and family. 48% knew that SCD is inherited, 44.2% did not know the cause of SCD while 68.7% of the respondents said they cannot marry a person with SCD. More than half of the respondents knew some signs and symptoms of SCD. Unfortunately, 50% did not know how SCD is diagnosed. The highest proportion (45.1%) of the respondents did not know the chance of having a healthy baby when both parents have SCT. Most (76.5%) of the respondents said that conventional medicine was the ideal treatment for SCD. There is insufficient public health awareness about SCD. Despite having heard of the disease, a relatively lower proportion had knowledge on the causes, signs and symptoms and prevention and this indicates a much larger problem.

Health care provider communication with caregiver's affects the level of knowledge that a caregiver will have. Barriers to communication included short consultation time (41.2%), use of technical terms by health workers (18.2%), and lack of privacy (10.7%), this was according to research carried out at Kenyatta national hospital in Kenya among caregivers of children with SCD. Additionally, perceived communication barriers reported by health workers included high workload 86.8%), insufficient time (55.9%) and lack of training on communication skills (27.9%).

Research done in Ogun state, Nigeria (which has the largest sickle cell gene pool in the world) indicated that only 39.0% of parents of SCD children had adequate knowledge of SCD, 75.2% on prevention of crisis, 62.0% on precipitating factors of sickle cell crisis and about 68.0% of participants' source of information was the hospital staffs. 74.7% felt guilty and responsible for the child's illness, 15.7% were tired of caring for SCD child, and 8.7% wished the child should just die. 2.4% believed it's a spiritual attack, 20% believed there is traditional treatment that can cure the disease, 15.7% had tried traditional methods of treatment, 11.8% have used concoctions, 1.2%did rituals, and 2.7% used traditional charms. Further, factors that influenced the level of knowledge included parents level of education and source of information about SCD while predictors of low frequency of crisis included individuals who had parents who attend tertiary education, information from health workers and family income above minimum wage [16].

National review

In Zambia, research with regards to SCD has been limited such that even information on prevalence is not comprehensive. Effective dissemination of SCD information among caregivers of SCD patients has been a challenge, hence this affects the attitudes and practices they have towards SCD. Research at UTH revealed that 83% of caregivers of SCD children had low levels of knowledge on the disease which affected their understanding of the disease and negatively influenced the way they cared for the affected child. This was attributed to low level of education (70%), lack of educational materials on SCD and low monthly income. Another study in Chilubi district, most of mothers to SCD patients had poor knowledge about SCD and only 60% could name an example of the type of sickle cell crisis that could lead to death in young children and majority advocated for the use of traditional remedies at home when their children have SCA crises.

SCD is one of the top most causes of admissions in the paediatric ward at KTH. These children come in sickle cell crises; one explanation is that there is lack of adequate knowledge among the caregivers with regards to prevention of these crises; however no studies have been done to justify this assumption. Only 2 studies have been done in Zambia on KAP'S of caregivers of SCD; however none has been done in Kitwe District. Most SCD care programs provide health education sessions for parents/caregivers at diagnosis and during follow up care clinics but there is limited information on how this practice increase the level of knowledge and adherence to recommended preventative interventions. Therefore, finding out the KAP's of caregivers of children with SCD towards SCD at KTH will contribute to filling the knowledge gap.

Materials and Methods

Objectives

General objective: To evaluate the knowledge, attitudes and practices of care givers of children with sickle cell disease towards sickle cell disease at Kitwe teaching hospital in Kitwe, Zambia.

Specific objectives

- To determine the level of knowledge on factors that precipitate sickle cell crises among care givers with children suffering from sickle cell disease at KTH.
- To assess the attitudes of care givers of children with SCD towards prevention of sickle cell crises at KTH.
- To describe the practices that care givers of children with SCD do in order to reduce the frequency of sickle cell crises at KTH.
- To determine the factors that influences the care givers level of knowledge, attitude and practice towards SCD at KTH.

Research question

What are knowledge, attitude and practices of care givers of children with sickle cell disease towards sickle cell disease at Kitwe teaching hospital in Kitwe, Zambia?

Measurement

Operational definitions

- **Sickle cell disease:** A group of inherited disorder of mutant hemoglobin that causes characteristic sickling of red blood cells.
- **Knowledge:** Information, understanding and skills that you gain through education or experience.
- **Practice:** The way of doing something that is the usual or expected way in a particular situation or organization.
- **Attitude:** A feeling or way of thinking that affects a person's behavior.
- **Caregiver:** A family member or paid person who gives care to people who need help taking care of themselves.
- **Children:** Young people of either sex between the ages of 6 months to 20 years of age.
- **Sickle cell crises:** Episodes experienced by a patient when there is a reduction of oxygen flow to the tissues precipitated by anemia, infection dehydration or sickled blood cells block the blood vessels (Table 1 and Figure 1).

Dependent variable	Scale	Indicator
Knowledge	Ordinal	Adequate knowledge on what SCD is and factors that precipitate sickle cell crises. Inadequate knowledge on what SCD is and factors that precipitate sickle cell crises
Attitude	Ordinal	Good attitude towards prevention of sickle cell crises. Poor attitude towards prevention of sickle cell crises.
Practice	Ordinal	Good practice towards reduction of frequent sickle cell crises. Poor practise towards reduction of frequent sickle cell crises.
Independent variables		
Age	Ratio	Teenager (15-19 years) young adult (20-30 years) adult (30 years and above).
Information and education given to caregivers	Ordinal	Adequate and correct information given on prevention of sickle cell crises. Inadequate and incorrect information given on prevention of sickle cell crises.
Caregivers level of education	Ordinal	Never been to school, grade 7, grade 9, grade 12, tertiary.
Financial income	Ratio	High (above k 3000 per month); medium (k 1000 to k 3000 per month; low (less than k 1000 per month).
Cultural and social beliefs	Ordinal	Negative-use of social and cultural practices towards prevention of sickle cell crises; Positive no use of social and cultural practices towards prevention of sickle cell crises.

Table 1. Shows variables that were measured when conducting the research.

Conceptual framework

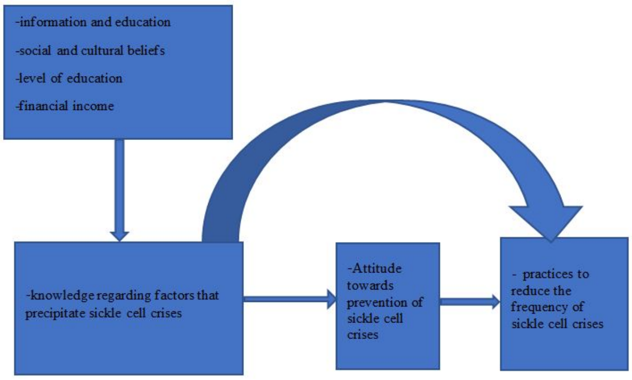

Figure 1. Conceptual framework.

Study site

The study took place at Kitwe teaching hospital in Kitwe, copperbelt province in Zambia. This is because the site was easily accessible and it provided the needed population for this study.

Target population

The target population was all caregivers of children with sickle cell disease attending the sickle cell disease clinic at Kitwe teaching hospital in Kitwe. This is because Kitwe teaching hospital was among the few hospitals that have a sickle cell disease clinic and one of the largest referral hospitals. This helped give a picture of the knowledge, attitude and practices of care givers of children with sickle cell disease towards sickle cell disease.

Study design

A cross-section study design was used to conduct the research. This type of study design was appropriate because it is quantitative hence the results gotten from the research were representative of the whole study population.

Sample size

Sample size was calculated using the formula below.

$n=p(1-p)\ (Z/E)^2$

Where;

n was the sample size required (?),

Z was the level of confidence measure (=1.96 at 95% confidence level),

p was the proportion of the population having the characteristic (estimated at 18% prevalence),

E was the margin of error (=0.05=5%).

Therefore $n=0.18\ (1-0.2)\ (1.96/0.05)^2$

$n=226.808064$

$n=227$

Therefore the required sample size was 227.

Sampling procedure

The non-probability sampling techniques were used because the target population was unknown. The convenient sampling was used to select the hospital in order to have a facility that contains the desired characteristics and was easily accessed while the purposive sampling was used for selection of participants to obtain the best information needed to achieve the objectives of the study.

Inclusion and exclusion criteria

Inclusion criteria: All care givers of children (6 months to 20 years) with sickle cell disease attending the SCD clinic at KTH. All participants had to give consent to participate.

Exclusion criteria

- All caregivers with children not suffering from SCD.
- All caregivers of children with newly diagnosed SCD *i.e.* <1 month.
- All caregivers of children with SCD but the children are <6 months or >20 years.

Data collection

A pre-tested, structured and self-administered questionnaire was used to collect the data. It was prepared in english coupled with the interviews for subjects that do not read and write as well as interviews of medical personnel at the sickle cell disease clinic.

Data analysis

Data collected from questionnaires was checked for possible errors before computerization. Quantitative data was analyzed using the SPSS version 22.0. Pearson's *chi-square* test was used to find association between independent and dependent variables with 95% confidence interval and a p-value of 0.05 was considered.

Study limitation

The population of study was composed of caregivers to children with SCD at Kitwe teaching hospital in Kitwe, therefore, the findings from this study cannot be generalized to all caregivers to children with SCD in Zambia. To add on, knowledge, practices and attitudes were self-reported hence; there is possibility of information bias because some information reported might be the ideal situation and not really what is practiced. Therefore, we cannot draw a predictive conclusion based on these differences.

Data analysis

The focus for this chapter is data analysis of the main findings with respect to the research questions. Assessment of the knowledge, attitudes and practices of caregivers of children with sickle cell disease towards sickle cell disease at Kitwe teaching hospital in Kitwe, Zambia. Data collected from questionnaires was checked for possible errors before computerization. Quantitative data was analyzed using the SPSS version 22.0. Pearson's *chi-square* test was used to find association between independent and dependent variables with 95% confidence interval and a p-value of 0.05 was considered. Section A discusses the social demographic characteristics, section B the knowledge of caregivers of children with SCD on prevention of sickle cell crises, section C the practices of caregivers on prevention of sickle cell crises, section D the social and cultural practices of caregivers on prevention of sickle cell crises while section E looks at the attitudes of caregivers towards prevention of sickle cell crises. The final section focuses on factors that influence the caregiver's level of knowledge, attitude and practices towards prevention of sickle cell crises.

Results

Social and economic demographic characteristics

Response and attrition rate: Questionnaires were randomly distributed among caregivers of children with SCD at KTH. The total number of potential respondents was Two hundred and twenty-seven (227) which the targeted sample size was. However, one hundred and ninety-two (192) questionnaires were analyzed. 10 (4.4%) participants refused to participate in the study while 25 (11.0%) of the questionnaires were not completely answered, resulting in the response rate of 84.58% and an attrition rate of 15.42%.

Social demographic characteristics: Majority of the caregivers were 35 years and above (56.3%), 78.1% were married and most of them had 1-3 children (65.6%). 75% had 1 child with sickle cell disease, 21.9% had 2 while 3.1% had 3 children with SCD. The proportion of primary, secondary and tertiary education was 40.6%, 46.9% and 6.3% respectively while 6.3% had never been to school. Further, most of the respondents were doing business (62.5%) as a source of income while 25% and 12.5% were unemployed and formally employed respectively. 65.6% had an income below K 500 and majority (65.6%) said the income was inadequate to take care of the needs of the sickle cell child (Table 2).

Variable		Frequency (n=192)	Percentage (%)
Age	15-19	12	6.3
	20-24	18	9.4
	25-29	12	6.3
	30-34	42	21.9
	35 and above	108	56.3
Marital status	Single	30	15.6
	Married	150	78.1
	Divorced	6	3.1
	Widowed	6	3.1
Number of children	1-3	126	65.6
	4-6	36	18.8
	7-9	24	12.5
	More than 9	6	3.1
Number of children with sickle cell disease	1	144	75
	2	42	21.9
	3	6	3.1
Level of education	Never been to school	12	6.3
	Primary school	78	40.6
	Secondary school	90	46.9
	College	12	6.3
Occupation	Formal employment	24	12.5
	Business person	120	62.5
	Unemployed	48	25
Income per month	Below K 500	126	65.6
	K 500 to K 999	30	15.6
	K 1000 to K 3000	24	12.5
	Above K 3000	12	6.3

Is the income adequate to take care of the child	Yes	66	34.4
	No	126	65.6

Table 2. Shows distribution of the social and economic demographic characteristics.

Knowledge on sickle cell disease and prevention of sickle cell crises

What is sickle cell disease?: Figure 2 shows caregivers responses to what sickle cell disease is.75% said SCD is a genetic disease of the red blood cell, 25% said it is a common blood disorder while no one picked SCD as a bleeding disorder.

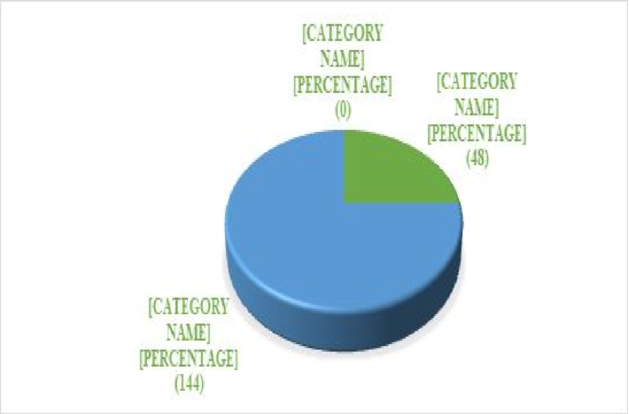

Figure 2. Definition of sickle cell disease.

What is sickle cell crises?: Figure 3 shows that majority (65%) of the caregivers were able to define sickle cell crises correctly *i.e.* episodes experienced by a patient when there is a reduction of oxygen flow to the tissues precipitated by anemia, infection dehydration or sickled blood cells block the blood vessels.35% were unable to answer correctly.

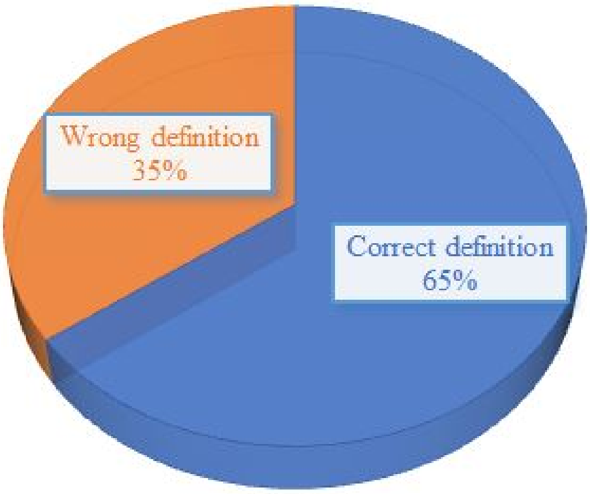

Figure 3. Definition of sickle cell crises.

What are the symptoms of sickle cell crises?: From Table 3, it is evident that the common symptom known by the caregivers is pain represented by 43.5% while difficulties in breathing was known by only 34.8% of the respondants. 21.7% of the respondents choose diarrhea (8.7%) and vomiting (13.0%) as symptoms.

Variable	Responses (n)	Percentage (%)	Percent of cases (%)
Pain	180	43.50%	93.80%
Difficulties in breathing	144	34.80%	75.50%
Diarrhea	36	8.70%	18.80%
Vomiting	54	13.00%	28.10%
Total	414	100.00%	215.60%

Note: The total does not add up to 192 because of multiple responses.

Table 3. Shows distribution responses to what are the symptoms of sickle cell crises?

Are sickle cell crises preventable?: Almost all the respondents (97%) agreed that sickle cell crises are preventable, only 3% said that they cannot be prevented. This is shown in Figure 4.

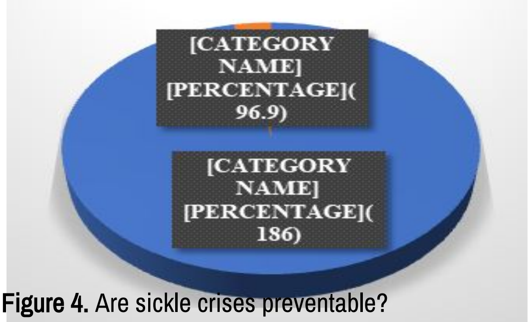

Figure 4. Are sickle crises preventable?

Predisposing factors to sickle cell crises: Figure 5 shows that the common predisposing factor known is exposure to cold represented by 23.1% followed by infection (20.1%).The averagely known predisposing factors include fever, dehydration and doing activities demanding more oxygen. However, 6% represented caregivers who choose sleeping under a mosquito net as predisposing factor.

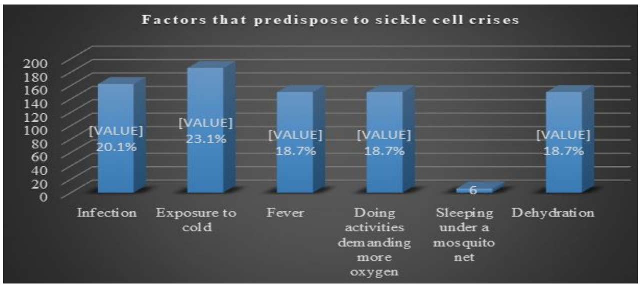

Figure 5. Predisposing factors to sickle cell crises.

Note: The total does not add up to 192 because of multiple responses.

Source of information on sickle cell crises prevention: Table 4 indicates that most (44.1%) of the respondent's source of information was the hospital staff, followed by 25% of respondent's source of information being the radio/television. Only 8.8% got their information from reading books and the internet.

Variable		N	Percent	Percent of cases
What is your source of information	Hospital	180	44.10%	93.80%
	Books	36	8.80%	18.80%
	Internet	36	8.80%	18.80%
	Radio/television	102	25.00%	53.10%
	Neighbors/relatives	54	13.20%	28.10%
Total		408	100.00%	212.50%

Note: The total does not add up to 192 because of multiple responses.

Table 4. Shows distribution of source of information on prevention of sickle cell crises.

Adequacy of information given by hospital staff: Figure 6 shows that most (78.1%) of the caregivers stated that information given by hospital stuff on prevention of sickle cell crises was adequate while 21.9% indicated that the information was inadequate.

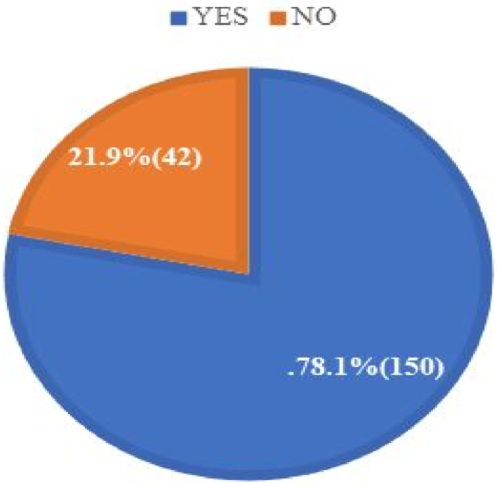

Figure 6. Shows distribution of the adequacy of the source of information.

Overall assessment of the level of knowledge on factors that precipitate sickle cell crises among care givers with children suffering from sickle cell disease at KTH: To assess knowledge, 4 questions were answered with 2 of the questions being multiple response questions consisting of 4 and 6 options respectively. A total score of 12 was used. The questions ranged from basic information regarding sickle cell disease to factors that precipitate sickle cell crises. One point was given to a correct response and zero for an incorrect response. An overall knowledge was calculated of which a score of 0-5 represented poor knowledge, 6-10 represented average knowledge and a score of 10-12 represented good knowledge (Table 5). Majority of the respondent representing 126 (65.6%) had good knowledge on prevention of sickle cell crises, 42 (21.9%) had average knowledge while 24 (12.5%) had poor knowledge as shown in Figure 7.

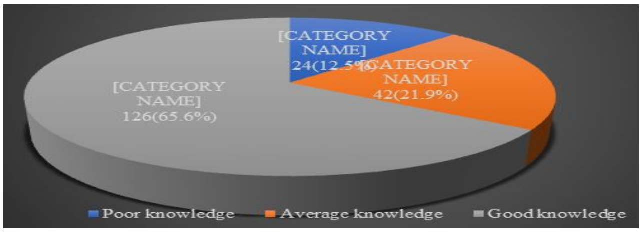

Figure 7. Knowledge levels of respondents regarding prevention of sickle cell crises.

Measure	Value
Mean	10.09
Median	11
Mode	12
Standard deviation	2.43

Table 5. Statistics on the level of knowledge of respondents.

Practices of caregivers of children with sickle cell disease on prevention of sickle cell crises

Do you take action to prevent sickle cell crises?: It is evident from Table 6 that most (93.8%) of the respondents took deliberate actions at home to prevent sickle cell crises while only 6.3% did not engage in any home practice to prevent sickle cell crises.

Response	Frequency (n)	Percentage (%)
Yes	180	93.8
No	12	6.3
Total	192	100

Table 6. Shows distribution of home prevention of sickle cell crises.

Measures taken to prevent sickle cell crises: From Figure 8, the most commonly known recommended preventive measure of sickle cell crises is giving the child plenty of fluids represented by 17.1% (192) and the least known is feeding the child nutritious food represented by 13.9% (156). However, 6.4% (72) of the respondents chose taking the child to a traditional healer as a preventive measure of sickle cell crises.

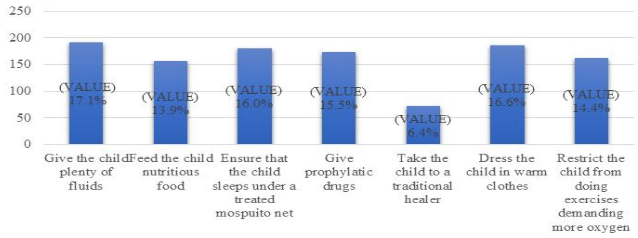

Figure 8. Prevention of sickle cell crises.

Note: The total does not add up to 192 because of multiple responses.

Overall measure of practices of caregivers towards prevention of sickle cell crises: To assess the practices of caregivers towards prevention of sickle cell crises, 2 questions were answered with 1 of the questions being multiple response question consisting 7 options. A total score of 8 was used. The questions consisted of questions enquiring on what practices the care givers engage in to prevent sickle cell crises. One point was given to a correct response and zero for an incorrect response. 0-5 represented bad practices, 6-8 represented good practices. Majority of the respondent representing 162 (84.4%) good practices towards prevention of sickle cell crises while 30 (15.6%) had bad practices as shown in Table 7.

		Frequency	Percent
Practices	Bad practice	30	15.6
	Good practice	162	84.4
	Total	192	100

Table 7. Practices towards prevention of sickle cell crises.

Social and cultural practices on prevention of sickle cell crises

Awareness of any negative social and cultural practices towards prevention of sickle cell crises: The results in Figure 9 depicts that majority 69% (132) were not aware of any negative social and cultural practices towards the prevention of sickle cell crises while 31% (60) indicated that they were aware of some of these practices.

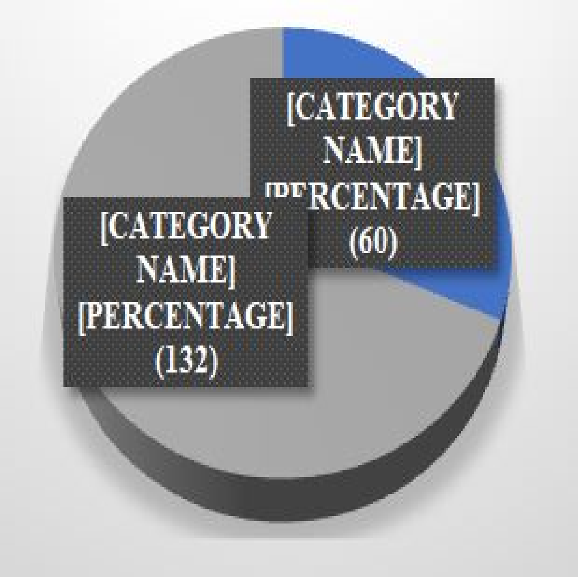

Figure 9. Awareness of any negative social and cultural practices towards prevention of sickle cell crises.

Known social and cultural practices towards prevention of sickle cell crises: Figure 10 shows that among the 60 that said yes to being aware of negative social and cultural practices towards prevention of sickle cell crises, 56.7% (34) knew about use of herbal medication, 26.6% (16) knew about use of soaked roots while 16.7% (10) knew about the use of cooked flowers.

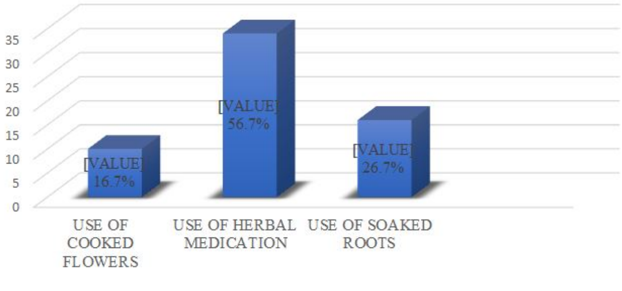

Figure 10. Known social and cultural practices towards prevention of sickle cell crises.

Ever practiced any of the cultural measures of preventing sickle cell crises

Figure 11 shows that 90% (54) of the respondents who knew some of the cultural preventive measures actually practiced them while 10% (6) did not engage in the practice of these cultural measures.

Figure 11. Distribution of practicing any of the cultural measures of sickle cell crises.

Attitudes of caregivers towards prevention of sickle cell crises

Are the preventive measures of sickle cell crises difficulty to put into practice?: Most of the respondents 65.6% (126) noted that the prevention measures are not difficulty to carry of, however 34.45 (66%) said they are difficulty to carry out (Table 8).

Response	Frequency (n)	Percentage (%)
Yes	66	34.40%
No	126	65.60%

Table 8. Shows the distribution of whether the sickle cell crises prevention measures are difficulty to put into practice or not.

What do you do when the child falls sick?: From Table 9, 83.3% (180) had positive attitudes towards prevention of sickle cell crises as they rushed to the hospital when the child fall sick. 16.5% (13.9%+2.6%) had a negative attitude as they either took the child for prayers or just stayed at home.

Variable	Frequency	Percentage	Attitude
Rush the child to the hospital	180	83.30%	Positive attitude
Take the child for prayers	30	13.90%	Negative attitude
Stay at home	6	2.60%	Negative attitude
Note: The total does not add up to 192 because of multiple responses.			

Table 9. What do you do when the child falls sick?

How caregivers feel having a child with sickle cell disease: Table 10 shows that 9.4% (18) of the respondents felt that the child should just die because they are tired of taking care of them while majority 90.6% had never had such a feeling.

Response	Frequency(n)	Percentage
Yes	18	9.40%
No	174	90.60%

Table 10. Have you ever felt that the child should just die because you are tired of taking care of them?

Factors that influence caregiver's level of knowledge, attitude and practices towards sickle cell crises prevention

Level of knowledge in association with study variable: Table 11 shows that there was an association between the level of knowledge and social demographics which included age, level of education, monthly income, adequacy of information and social cultural practices as all these had a p-value<0.05 from the chi square test.

An analysis of age with knowledge showed that those aged 35 and above scored the best in the category of those with good knowledge represented by 57.1% compared to that age 25-29 and 15-19 who scored 4.8% and 0.0% respectively. Further, cross tabulation of level of knowledge with level of education showed that those with poor knowledge 25% (6) of them had never been to school while 75% (18) of them had primary education as their highest level of education. Additionally, 75% (18) of those with poor knowledge had an income of <K 500, 25% (6) had an income of K 500-K 999 while 0.0% of those with an income of K 3000 and above had poor knowledge. Furthermore, among those with poor knowledge 50% noted that the information they received the health personal was adequate while 50% said the information was not adequate. Lastly, among those with good knowledge 61.7% (78) did not engage in social cultural practices while 38.1% did engage in social cultural preventive measures of sickle cell crises.

		Average knowledge	Good knowledge	Poor knowledge	p-value
Age	15-19	14.3% (6)	0.0% (0)	25.0% (6)	P<0.001
	20-24	14.3% (6)	9.5% (12)	0.0% (0)	
	25-29	0.0% (0)	4.8% (6)	25.0% (6)	
	30-34	14.3% (6)	28.6% (36)	0.0% (0)	
	35 and above	57.1% (24)	57.1% (72)	50% (12)	
Level of education	Never been to school	0.0% (0)	4.8% (6)	25.0% (6)	P<0.001
	Primary school	42.9% (18)	33.3% (42)	75.0% (18)	
	Secondary school	57.1% (24)	52.4% (66)	0.0% (0)	
	College	0.0% (0)	9.5% (12)	0.0% (0)	
Income/month	Below K 500	71.4% (30)	61.9% (78)	75.0% (18)	0.004
	K 500 to K 999	0.0% (0)	19.0% (24)	25.0% (6)	

	K 1000 to K 3000	14.3% (6)	14.3% (18)	0.0% (0)	
	Above K 3000	14.3% (6)	4.8% (6)	0.0% (0)	
Adequacy of information	Yes	71.4% (30)	85.7% (10)	50.0% (12)	0.001
	No	28.6% (12)	14.3% (18)	50.0% (12)	
Social cultural practices	Yes	0.0% (0)	38.1% (48)	25.0% (6)	P<0.001
	No	100% (42)	61.9% (78)	75.0% (18)	

Table 11. Shows level of knowledge in association with study variable.

Level of knowledge in association with attitude: Table 12 shows that there was a significant association between level of knowledge and attitude as seen by p-value of <0.001. 85.7% (108) of those with good knowledge had a good attitude towards sickle cell crises prevention while only 14.3% of those with good knowledge had a bad attitude.

Variable	Average knowledge	Good knowledge	Poor knowledge	P-value
Bad attitude	42.9% (18)	14.3% (18)	50.0% (12)	P<0.001
Good attitude	57.1% (24)	85.7% (108)	50.0% (12)	
Total	100.0% (42)	100.0% (126)	100.0% (24)	

Table 12. Cross tabulation of level of knowledge with attitude.

Level of knowledge in association with practice: A p-value of <0.001 showed that there was significant association between level of knowledge and practices. Additionally, cross tabulation of the two variable showed that 95.2% of those with good knowledge had good practice while only 4.8% had bad practice. Further 75% of those with poor knowledge had bad practice while only 25% of those with poor knowledge had good practices towards prevention of sickle cell crises and it is shown in Table 13.

Variable	Average knowledge	Good knowledge	Poor knowledge	P-value
Bad practice	14.3% (6)	4.8% (6)	75.0% (18)	P<0.001
Good practice	85.7% (36)	95.2% (120)	25.0% (6)	
Total	100.0% (42)	100.0% (126)	100.0% (24)	

Table 13. Cross tabulation of level of knowledge with practice.

Attitude in association with practice: Table 14 shows that there is a significant association between attitude and practice as evidenced by a p value of <0.001. Additionally, cross tabulation of the aforementioned variable showed that 91.7% (132) of those with good attitude had good practice while only 8.3% (12) of those with good attitude had bad practice.

Variable	Bad attitude	Good attitude	P-Value
Bad practice	37.5% (18)	8.3% (12)	P<0.001
Good practice	62.5% (30)	91.7% (132)	
Total	100.0% (48)	100.0% (144)	

Table 14. Cross tabulation of attitude with practice.

This study sought to evaluate the levels of knowledge, attitude and practices among caregivers of children with sickle cell disease towards sickle cell disease at Kitwe teaching hospital in Kitwe, Zambia. The main findings are now discussed in this chapter as well as the conclusion and recommendations.

Discussion

This study showed that 65% of the caregivers had good knowledge, 21.9% had average while 12.5% had poor knowledge. This was inconsistent with the findings of a study at ADH, Ndola was 19% had poor knowledge, 54.2% had average and 26.9% had good knowledge. The difference would due to difference in questions used to assess knowledge and difference in scales used to grade the knowledge.

Additionally, it was found that 65% of the respondents were able to define SCC correctly, further the commonest known predisposing factor to SCC was exposure to cold (23%) followed by infection (20.1%). These results are in line those found in a study done at UTH were 72% of the respondents defined SCC correctly and exposure to cold and infection were the commonest known predisposing factor represented by 34% and 19% respectively.

Research at UTH among caregivers of SCD children attributed low levels of knowledge to low level of education (70%), lack of educational materials on SCD and low monthly income. Further another study in Nigeria showed that factors that influenced the level of knowledge included parents level of education and source of information about SCD. This is similar to what was found in the current research where factors that influenced the level of knowledge were age, level of education, monthly income, adequacy of information given by health workers and social cultural practices as there was a significant association (p-value<0.05) between the aforementioned variables and the level of knowledge.

According to Jaffer et al, knowledge about SCD and precipitating factors of sickle cell crises affect attitude, hence caregiver's knowledge regarding sickle crises preventive measures is correlated with their attitude toward preventive practices. 83.3% of participants in this research had a good attitude and only 16.5% had a negative attitude. This is in contrast with another study in Chilubi where majority had a bad attitude as they advocated for the use of traditional remedies at home when their children have SCA crises. However a study at ADH showed that 92.5% of the caregivers had a positive attitude which is similar to the current study. Lastly, the level of knowledge was associated (p<0.001) with attitude as 85.4% of those with good knowledge had good attitude and 50% of those with poor knowledge had bad attitude.

Most (84.4%) respondents had good practices towards prevention of sickle cell crises, the commonest being giving the child plenty of fluid. Likewise, a study at UTH showed that most (64%) of the respondents had good practice as well as the another study at ADH were 88.9% had good practice. 15.6% of the respondents had bad practice which included taking the child to a traditional healer as a preventive measure of SCC. Additionally, others took part in the use of herbal medication where they used different flowers and roots to make concoctions. These were similar findings in Ogun state, Nigeria (which has the largest sickle cell gene pool in the world) were 15.7%had tried traditional methods of treatment, 11.8% have used concoctions, 1.2% did rituals, 2.7% used traditional charms. Factors that influenced the type of practice included level of knowledge as it was found that three quarters of those with poor knowledge had engaged in bad practice as shown in Table. To add on, the attitude the caregivers had towards SCC prevention also influenced what practices they were took part in Table.

Conclusion

This project revealed that 65.6% of the caregivers had good knowledge on SCD and prevention of SCC with majority having good attitudes and practices towards prevention of SCC. Additionally, age, level of education, monthly income, information and education about SCC prevention and social and cultural practices are factors that influenced the level knowledge which intern affected the attitude and practices engaged towards prevention of SCC. Despite advancements in educating caregivers of SCD children, this study revealed that there are still many gaps to be filled regarding the knowledge, attitude, and practice associated with SCD and prevention of SCC.

Recommendations

In view of the study outcomes, Government through Ministry of health should implement effective education on SCD and prevention of SCC through intensified sessions with SCD patients and the caregivers. Additionally, easily understandable literature should be given to caregivers to take home for better understanding of the disease and more dissemination of information about SCD and prevention of SCC through social media, internet, radio/television and community visits should be implemented. Further, formation of organizations that can provide psychological, social as well as avenues for income generating activities for financial support to the patients and their immediate families who are unable to engage in SCC preventive measures due to financial challenges. Lastly, research on the knowledge, attitude and practices of health providers towards SCD and prevention of SCC should be carried out.

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Ethical Consideration

The proposal was reviewed by the ethics committee based at tropical diseases research centre, ndola through the Copperbelt university school of medicine authorities. Further, permission was sought from the provincial health offices of copperbelt province and the management of Kitwe teaching hospital to conduct this study. All participants read the information sheet and signed the consent form in order to take part in the research. The entire participant who wished to withdraw from the study was allowed to do so (Appendix 1-9). Furthermore, names or identification numbers of participants were not being included in the study. Lastly, the information collected from participants was used strictly for academic purpose and no reward was given for participation.

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