

## Knowledge and Practices of Caregivers Towards Home-Based Care of Sickle Cell Anaemia Among Children Below Ten Years of Age Attending Jinja Regional Referral Hospital, Jinja City

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### ABSTRACT

Sickle cell disorders can be managed cost-effectively by programs that integrate treatment with early carrier detection through screening and genetic counselling. However, sickle cell disease is not well known or recognized by many individuals as a significant health problem with major complications, thus a large number of Ugandans are carriers of the trait but they are unaware of their status. Therefore, this study sought to determine the knowledge and practices of mothers towards the home-based care of sickle cell anaemia among children below 10 years at Jinja regional referral hospital in Jinja City. Simple random sampling was used to select the required number of participants, n equals 30. The questionnaire used consist of closed and open-ended questions to collect both qualitative and quantitative data. The data was analysed using descriptive statistics and presented in tables and figures. The study findings revealed that 59.3% of respondents had poor knowledge while 40.7% of respondents had good knowledge concerning home-based care of their children with SCA. 52.9% of the respondents had good practices while 47.1% had poor practices about home-based care of their children with SCA. So, it was concluded that caregivers lack adequate knowledge about home-based care of children with SCA with average good practices. Therefore, there is a need for government to come up with programs aimed at teaching mothers and the communities at large to impact knowledge on how to manage SCA. Health education should be done regularly and expanded to couples intending to marry and also screened during antenatal visits. There is also a need for more sensitization of the general public both by the government and professionally experienced health workers pertaining SCD in Uganda.

**Keywords:** Sickle cell anaemia, Genetic counselling, Significant health problem, Children below 10 years, Mothers, Health workers.

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### INTRODUCTION

Sickle cell disease (SCD); Defines a set of hereditary haemoglobin disorders characterized by a high proportion of abnormal sickle haemoglobin in the red blood cells. Sickle cell Anaemia (SCA) which is the most common and most serious form of sickle cell disease (SCD) results from homozygous inheritance of the sickle haemoglobin Gene (S) from both parents and such a person presents with signs and symptoms of the disease. [1]. It is an autosomal recessive hereditary anaemia characterized by the presence of sickle-shaped red blood cells and by

accelerated Hemolysis due to the substitution of a single amino acid glutamic acid by valine at position 6 of the beta chain. [2]. Red blood cells (RBCs) have crescentic/sickle shape due to the deformation of the normal red blood shape by intracellular polymerisation when these sickled red blood cells get deoxygenated. This leads to them being detected and destroyed by the spleen resulting in hemolytic anaemia. Other symptoms of the disease include vaso-occlusion that characteristically causes tissue ischemia, severe pain and acute chest syndrome and

as well organ failure among others [3] Globally the Meta estimate for the birth prevalence of heterozygous SCD was 4229.72% per 100,000 live births with the highest birth prevalence in Africa 16121.91% per 100,000 and lowest in Europe 803.57%, approximately 5% of world's population carriers' trait gene for sickle cell disease and thalassemia. [4]. Over 300,000 babies with severe haemoglobin disorders are born each year (2021 WHO/Regional Office for Africa). However, studies from Benin and Nigeria suggest mortality rates of up to 50% and 90% respectively. Major factors thought to contribute to the high mortality rate among children with SCD in Africa are the cultural background, lack of medical education and limited healthcare facilities [5].

Mostly in low- and middle-income countries with the majority of these birth in Africa, Nigeria has the highest population of people with sickle cell disease with about 150,000 children born with the disease yearly. [6] It was a haematological disorder present in most countries of sub-Saharan Africa in Tanzania between 50% to 75% of the children born with SCD die before reaching 5 years [7]. It is estimated that SCD affects approximately 100,000 Americans. SCD occurs among about 1 out of every 365 black American births. It occurs among about 1 out of every 16300 Hispanic American birth (CDC 16 December 2020) SCA is a major global public health concern of which sub-Saharan Africa bears a great load. More than 3 out of 4 all those affected worldwide are born within the region [8] 1 in 3 Ghanaians were said to have sickle cell disorder prevalence of sickly screening positive was 16.0% with an overall prevalence of sickle cell disorder being 2.0%. Among the individual genotype making up the sickle cell disorder, genotype HbSF was the highest 0.9% as compared to 0.2% HbSS, 0.6% HbSC and 0.3% HbSCF [9] WHO estimated that more than 300,000 babies are born with a severe form of Hemoglobinopathy each year. While 75% of that is in sub-Saharan Africa, Nigeria alone accounts for 100,000 new birth every year. Statement of the problem.

### Statement of Problem

It contributes up to a 15% mortality rate which stands at 64% per 1000 live birth. Sickle cell disease prevalence stands at 0.73% while sickle cell trait prevalence stands at 13.3%.

Carriers of SCT can easily be detected by routine haematological screening methods and can be forewarned about their reproductive risk and ways of how to reduce it [10].

In Uganda, most diagnoses of sickle cell are only made when the child presents with signs and symptoms of the disease. This in turn led to high morbidity and mortality due to sickle cell disease. The frequent hospital admissions due to emergencies of a crisis or routine health care coupled with increased demands from maintaining the health of their SCD-born children at home inclusive of their expected short life expectancy of the children put an enormous psychosocial and psychological stress on the parents of these children [11]. On average, a family will spend 111.67 US Dollars which is equivalent to about 402,000 Ugandan shillings per episode of an SCD crisis requiring hospital admission [12]. All the above can be avoided if people get to know about their SCT and make informed choices. The Uganda Ministry of Health conducted a nationwide sickle cell survey in 2014 and this showed a significantly high burden of sickle cell disease and trait in Uganda. The national sickle cell trait prevalence currently stands at 13.3% while disease prevalence stands at 0.73% (Ministry of Health of Uganda press statement on sickle cell Day 14. June 2017). 25000 babies born were estimated to have sickle cell disease annually, of which 80% died before their fifth birthday. Jinja district where this study was carried out has a high prevalence of SCT of 18.9% and it's among the 14 districts with a high SCD Burden [13] Therefore, there is a need to assess the knowledge and practices of caregivers towards home-based care of sickle cell anaemia at Jinja regional referral hospital, Jinja city.

### Aim of the study

To assess the knowledge and practices of caregivers towards home-based care of sickle cell Anaemia among children below

10 years at Jinja regional referral hospital, in Jinja City.

**Specific objectives**

- To assess the socio-demographic factors influencing the knowledge and practices of caregivers towards home-based care of sickle cell anaemia among children below 10 years attending Jinja regional referral hospital, Jinja City.
- To determine the knowledge of caregivers about home-based care of sickle cell Anaemia among children below 10 years at Jinja regional referral hospital, Jinja City.
- To identify the practices of caregivers towards home-based care of sickle cell Anaemia among

**METHODOLOGY**

**Study design**

A descriptive and cross-section study design will be used because it allows the researcher to obtain the necessary information within the shortest time and it is cost-effective.

**Area of Study**

Jinja city is located in Eastern Uganda and is bordered by Kamali district to the north, Luka district in the east, Mayuge District in the south-east and Buvuma district to the south, Buikwe district to the west and Kayunga district to the west. It is located along the Jinja-Kampala highway 2km off Nalufenya road. It is found in Jinja city, On Nalufenya road.

**Study population**

The study targeted caregivers and their children having sickle cell anaemia in the Paediatrics medical ward at Jinja Regional Referral Hospital in Jinja City.

**Accessible population**

Caregivers of children with sickle cell Anemia that fall in the age group of below 10 years attending Jinja Regional Referral Hospital.

**Sample size determination**

The sample size was determined by the formula below;

$$n = \frac{N}{1 + Ne^2}$$

Where:

N=sample size

e=0.05(level of significance/error margin)

N= population estimate

Considering the total population which

children below 10 years at Jinja regional referral hospital, Jinja City.

**Research questions.**

what are the socio-demographic factors influencing the knowledge and practices of caregivers towards home-based care of sickle cell anaemia among children below 10 years attending Jinja regional referral hospital, Jinja City?

What is the knowledge of caregivers about home-based care of sickle cell anaemia among children below 10 years attending Jinja regional referral hospital, Jinja City?

What are the practices of caregivers towards home-based Care of sickle cell anaemia among children below 10 years attending Jinja regional referral hospital, Jinja City?

was 30 respondents.

Then N=30, e=0.05

$$n = \frac{30}{1 + 30(0.05 * 0.05)} = 28$$

**Sampling technique**

The research used simple random sampling to select the required number of participants. In simple random sampling, the research makes a numbered list of all the units in the population from which to draw a sample. Each sub-unit should be numbered from 1 to N (size of the population) he l then decided on the size of the sample and selected the required number of sampling units using "the lottery method. The method is simple and minimizes bias in that it gives all sample populations an equal chance of participation in the study.

**Sampling procedure**

The study sample was taken using a simple random sampling method. The available respondents were selected randomly for the study. I then established the number of caregivers nursing children suffering from sickle cell anaemia through a clinical service supervisor then numbered 8 small pieces of paper one-eighth, folded them and mixed them thoroughly with blank pieces of paper to sum up the number of clients available. This was used to select the first respondent who shall have picked numbered papers and the process repeated once every day until the required number is reached. This was done to avoid bias.

### **Data collection method**

This study utilized primary and secondary sources of data.

Primary data was collected from caregivers nursing their children with sickle cell anaemia in the Paediatrics medical ward at Jinja regional referral hospital using a questionnaire.

### **Data collection tool.**

Data was collected using a standardized questionnaire. This was administered to the research participants by the researcher and the trained assistants. The questionnaire was organized in accordance with the study objectives and it consisted of four sections, 1) Social demographic details, 2) Home-based care of sickle cell Anemia, 3) Knowledge about sickle cell home-based care, 4) Practices towards sickle cell home-based care among children below ten years attending Jinja Regional Referral hospital. Most of the questions were close-ended and the caregivers had

to tick an option that best applied to them. A few open-ended questions were included so that I capture questions that could be missed by the close-ended questions. The questionnaire was first pre-tested in the Goma division of the n Mukono district to assess its validity and reliability. Validity was checked by consistency of responses, whereas reliability was assessed using the test-retest method. The majority of the questionnaire was written in English and a few were translated into Lusoga the most spoken language in the area. Trained Interpreters were available to guide respondents on how each question had to be approached and answered.

### **Data collection procedure**

Clearance and introduction letters were obtained from the university administration of Kampala International University-Western (KIU-WC), after which they were taken to the executive director of Jinja Regional Referral Hospital for permission and clearance to carry out research at this hospital. Three research assistants were selected from the hospital staff and personally trained by the researcher and showed how to collect data and handle the different aspects of the study. Caregivers attending Jinja Regional Referral Hospital were approached by the

researcher and his assistants, explained to them the purpose of carrying out the study, and the procedure and addressed any concerns. Those that agreed to participate in the study were asked to consent by either a signature or a thumbprint, after which they were asked to personally answer the questionnaire. Questionnaires were checked for completeness before being collected back and taken for storage. Meetings between the researcher and the assistants were held after every day of data collection so that questionnaires were handed over to the researcher and any challenges faced were addressed.

### **Piloting the study**

The data collection tool will be presented to a small number of caregivers outside the study area so as to ensure reliability and validity.

### **Quality control**

#### **Testing validity**

The data collected were passed to caregivers throughout the study to ensure reliability and validity. The questionnaire was then refined by the supervisor.

#### **Inclusion criteria**

The study included all caregivers nursing sickle cell children in the paediatric medical ward at Jinja regional referral hospital and willing to consent.

#### **Exclusive criteria**

All caregivers nursing sickle cell children but do not want to consent and all those who had critically ill children requiring ICU.

### **Data analysis and presentation**

In this study, descriptive statistics were used to analyze the data and the following techniques can be used;

#### **Computation of data**

Data collected was calculated manually by use of a scientific calculator

#### **Editing data**

The data collected was checked to detect and correct errors and omissions to ensure accuracy, uniformity and completeness. This was done by the researcher who saw that none of the questions have been skipped and all answers have been recorded correctly and all responses recorded are internally consistent with each other.

### **Cording of data**

The data was summarized in representative form. The related answers or responses to particular questions were classified into meaningful patterns and summaries. This was done to ensure that responses are put into categories or classes

### **Classification of data**

Data were arranged in groups or classes on the basis of column characteristics whereas by data of similar characteristics are placed in one class such that the

entire data gets divided into numbers of classes or categories.

### **Presentation of data**

This is the displaying or showing of the results or finding for consumption by another stakeholder. This was done by tabulation, graphics, and charts for further analysis.

### **Interpretation of data**

Represented data will be used as a basis for drawing conclusions or inferences and explaining their significance after careful analysis of collected data.

**RESULTS****The social demographic characteristics of the respondents****Table 1: Shows the social demographic characteristics of respondents n=30**

No	Social demographic characteristics	Frequency	percentage
1	Age		
	15-24	5	16.66
	25-34	20	66.66
	35-44	5	16.66
	>45	0	0
2	Socioeconomic class		
	Upper	2	6.66
	Middle	19	63.33
	Lower	9	30
3	Occupation		
	Civil servant	3	10
	Self-employed	9	30
	Housewife	5	16.66
	Others	13	43.33
4	Marital status		
	Single	2	6.66
	Married	20	66.66
	Divorced	8	26.66
	Widow	0	
5	Tribe		
	Musoga	12	40
	Muganda	5	16.66
	Mugwele	0	0
	Others	13	43.33
6	Formal education level		
	None	0	0
	Primary	18	60
	Secondary	9	30
	Tertiary	3	10
7	Religion		
	Catholic	9	30
	Christian	10	33.33
	Islam	11	36.66
	Others	0	0

Source: primary data, November 2022

**Age**

The findings indicated that most of the respondents 20 (66.66%) were aged 25-34 years, and 5(16.66%) were aged 15-24 and 35-44 years respectively.

**Socioeconomic class:**

The majority of the respondents 19 (63.33 %) were in the middle class, 9(30%)were in the lower class and 2 (6.66%) were in the upper class.

**Occupation**

The findings indicated that most of the respondents 13 (43.33%) follows in others, 9 (30%) was self-employed, 5 (16.66%) was housewife and 3 (10%) were civil servants respectively.

**Religion**

The majority of the respondents 11 (36.66%) were Moslems, 10 (33.33%) were Christians, 9 (30%) were Catholics.

**Marital status**

Of the respondents 20(66.66%) were married, 8 (26.66%) were divorced and 2 (6.66%) were single respectively.

**Tribe**

13 (43.33%) respondents belonged to others, 12 (40%) were biogas, and 5 (16.66%)were agendas.

**Formal education**

The results indicated that the majority of the respondents 18 (60%) attained primary education, 9 (30%) ended in secondary and 3 (10%) attained a tertiary level of learning.

**Knowledge of respondents about home-based care of SCA**  
**Table 2: Shows the knowledge of respondents about home-based t of SCA n=30**

No	Response	Frequency	Percentage
1	Have you ever heard about SCA		
	Yes	25	83.33
	No	5	16.66
2	Do You Know SCD Is Transmitted		
	Yes	9	30
	No	21	70
3	Is SCD In Your Family		
	Yes	7	23.33
	No	23	76.66
4	Have You Ever Screened For SCD		
	Yes	3	10
	No	27	90
5	Do You Know the Sickle Cell Status Of Your Husband		
	Yes	11	36.66
	No	19	63.33
6	Do You Know the Precipitating Factor Of Sickle Cell Crisis		
	Yes	4	13.33
	No	26	86.66
7	Know The Signs and Symptoms of SCD Crises		
	Yes	22	73.33
	No	8	26.66
8	SCD can be cured		
	Disagree	15	50
	Strongly disagree	5	16.66
	Strongly agree	10	33.33
9	Three symptoms of SCD crises Fatigue and joint pain or fever		
	Joint pain, fever and fatigue	11 19	36.66 63.33

**Source: primary data, November 2022**

According to the study findings, it was indicated that 25 (83.33%) respondents

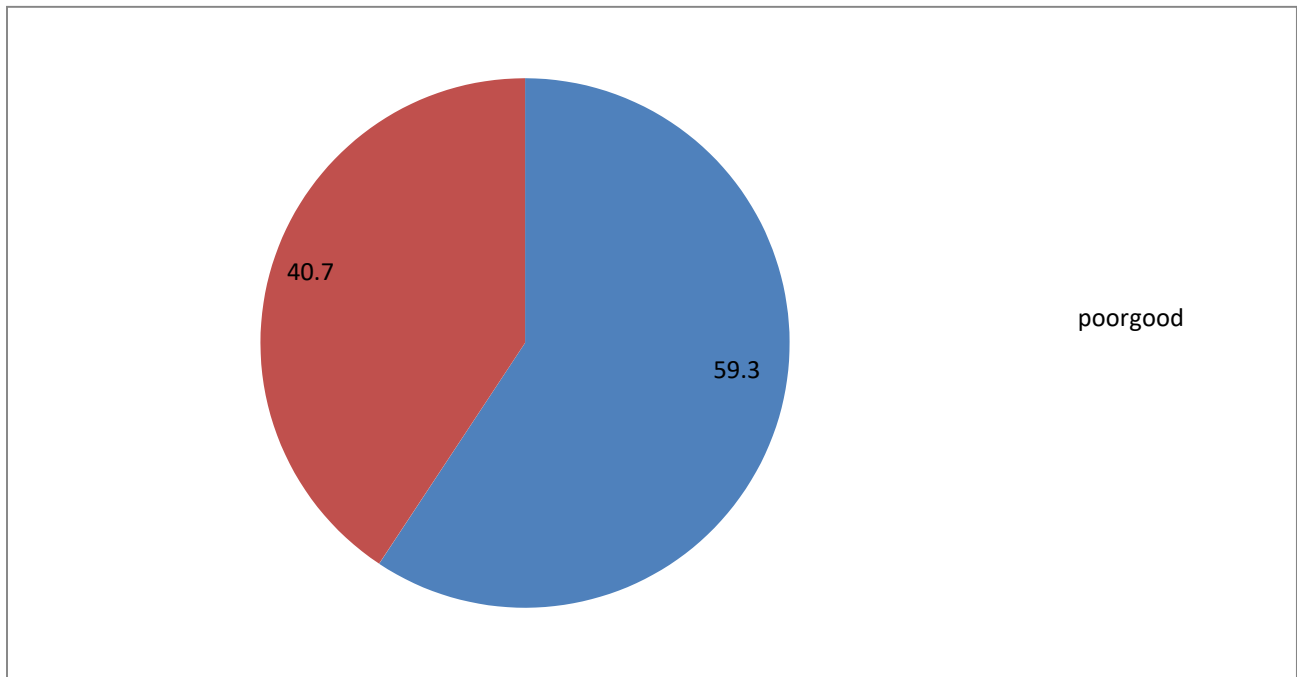
had never heard about SCA while 5 (16.66%) respondents never had any information



about SCA. In relation to how SCA is transmitted, 21 (70%) did not know while 9 (30%) knew its transmission. 23 (76.66%) respondents never knew the presence of SCA in their families while 7 (23.33%) reported the presence of SCA in their families. According to the research conducted, the majority of the respondents 27 (90%) had never screened for SCA before and 3 (10%) had ever screened. The study indicated that 19 (63.33%) were not aware of the sickle cell status of their husbands while 11 (36.66%) knew. The majority of the respondents 26 (86.66%) were not aware of the precipitating factors for the crisis of SCA

Matege while 4 (13.33%) were much aware of the precipitating factors. The study also showed that 22 (73.33%) respondents knew the signs and symptoms of SCA while 8 (26.66%) had poor knowledge about SCD. Of the 30 respondents who undertook the study, and were asked to state the three symptoms of sickle cell crisis, 19 (63.33%) mentioned all while 11 (36.66%) respondents only mentioned two symptoms.

The findings indicated that on the question asked that SCD can be cured, 15 (50%) respondents disagreed, 5 (16.66%) strongly agreed while 10 (33.33%) strongly disagreed.



**Figure1: A pie chart showing the knowledge of respondents on home-based care of children with SCA**

Bar graph showing the source of information about home-based care.

**Practices of respondents regarding home-based care of SCA**

**Table 3: Shows the practices of respondents regarding home-based SCA**

No	Response	frequency	Percentage
1	Do you take the child for Regular review?		
	YES	23	76.66
	NO	7	23.33
2	Does your child sleep under a treated Mosquito net?		
	YES	21	70
	NO	9	30
3	Is your child having malaria prophylaxis?		
	YES	4	13.33
	NO	26	86.66
4	Do you expose the child to cold weather?		
	YES	6	20
	NO	24	80
5	Is the child having a personal Jacket?		
	YES	20	66.66
	NO	10	13.33
6	Does the crisis affect the daily activities of Your child?		
	YES	28	93.33
	NO	2	6.66
7	Can you get married to person with sickle cell? YES	9	30
	NO	21	70

Sources: primary data, November 2022

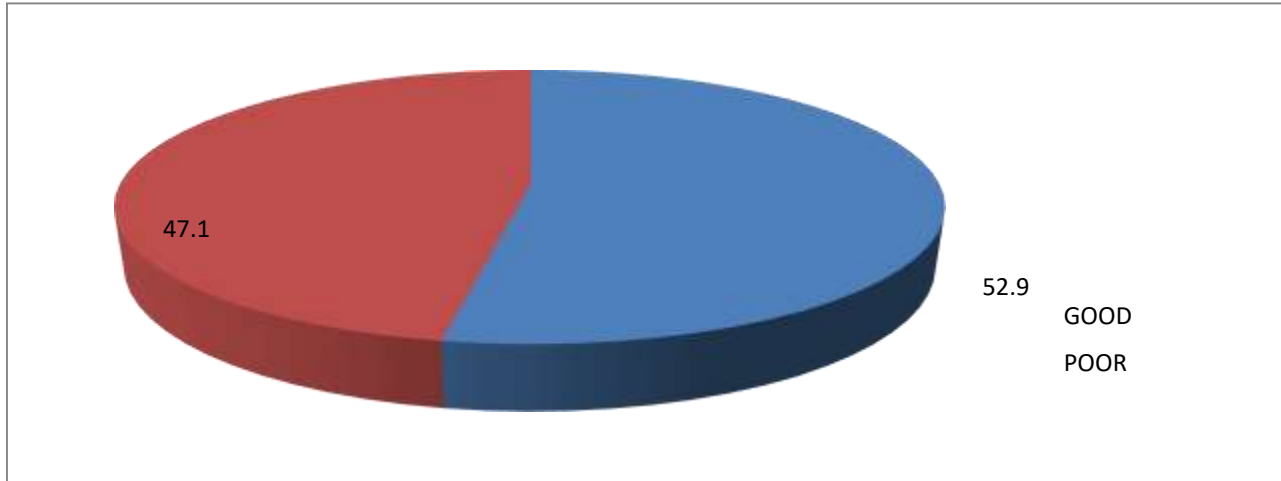
According to the study findings, the majority of the respondents 23(76.66%) take their children for regular review while 7(23.33%) don't take them. 21 (70%) make their children sleep under a treated mosquito net and only 9 (30%) respondents don't provide a mosquito

net to their children. The majority of the respondents 26(86.66%) give malaria prophylaxis to their children and only 4 (13.33%) did not provide the prophylaxis. 24 (80%) respondents do not expose children to cold weather while 6 (20%) used to expose

children to cold weather. Most of the respondents 20 (66.66%) report having a jacket for their children while 10 (33.33%) respondents do not provide a personal jacket

to their children. Almost all the respondents were aware that the crisis can affect the daily activities of their land only 2 (6.66%) never knew.

**Figure 2: A pie chart showing the practices of respondents about home-based care of children with SCA**



### DISCUSSIONS

#### **Social demographic characteristics of mothers about home base care of SCA**

The findings of the study indicated that the majority of the respondents 20 (66.66%) were aged 25 - 34 years demonstrating most mothers of middle reproductive age are potential carriers of sickle cell. In relation to this study, results by [6] showed that the majority of the respondents were of lower socioeconomic strata. The study demonstrated that the majority of the respondents 19 (63.33%) were of the middle-income class. On the contrary, a study by [8], indicated that it is highly distributed among high-income countries. The findings also showed a high frequency among the biogas 12 (40%) and others 13 (43.33%) whereas studies by [14] showed wide destruction among the African and American Negroes The majority of the respondents 187 (60%) only attained primary education while a study by [7] showed a significant correlation between total knowledge score and educational level and occupation. Other findings showed that the disease was more in married mothers .in contrary, a study by [15], showed that there was no significant association between the disease and

marital status.

#### **knowledge of caregivers towards home-based care of SCA**

The findings indicated that 25 (83.33%) respondents had never heard about SCA.in relation, to the study by [16] and [17], 91.2% and 94.2% respectively. The findings showed that mothers had poor knowledge regarding home-based care of children with SCA. While a study by [18] indicated that 28.8% of the respondents had good knowledge of SCA The study findings revealed that 73.33% knew the signs and symptoms of SCA however according to the study by [17][18] [19][20][21], 69.833% knew them. In another question which asked whether SCD can be cured, 50% disagreed, 16.66% strongly agreed and 33.33% strongly disagreed. Concomitantly in a study conducted by E.P.K Ameade et al, out of 190 respondents assessed, 73 disagreed, 75 strongly agreed and 42 strongly disagreed. The findings indicated that 19 (63.33%) respondents knew the three symptoms of sickle cell crisis Contrary to the study by [17], only 99 respondents managed to answer correctly. According to findings,9(30%) can get married to someone with sickle cell yet

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only 32 and 68.7% of respondents can do so according to the study by [17] and [16][22][23][24] [32][33].

### **Practices of caregivers towards home-based care of children with SCA**

The study findings indicated that 21 (70%) reported some drugs as prophylaxis however according to the study by [14],[25],[26][27] [28] 30% of the respondents were taking drugs. According to the study, 21(70%) cannot get married to

### **CONCLUSIONS**

The study sought to assess the knowledge and practices of caregivers towards home-based care of children below ten years of age attending Jinja Regional Referral Hospital with sickle cell anaemia. A Sample of 30 caregivers taking care of sickle cell children was used and the findings indicated that 40.7% of caregivers had good knowledge while 59.3% had poor knowledge about home-based care of children with SCA. From the study, it was found that 52.9% of the respondents had good practices about home-based care of children with SCA while 47.1% of respondents had poor practices. Therefore, it can be concluded that there is poor knowledge among respondents and fairly good practices pertaining to home-based care of children suffering from sickle cell anaemia.

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someone with sickle cell. in relation to this, only 68.7% said cannot marry a person with SCD according to the study conducted by [16][29][30][31][32][33]. The study findings showed that there were generally good practices by respondents which is almost similar to the study by [19] [18] and [32] indicating 90% and 19.1% of mothers had satisfactory practices regarding children with SCA.

### **Recommendations**

The following recommendations are drawn;

- The government should come up with programs aimed at teaching caregivers and the communities at large to impact knowledge on how to do home-based care of SCA.
- Health education should be done regularly and expanded to couples intending to marry and also screening during antenatal visits.
- There was a need for more sensitization of the general public both the government and professionally experienced health workers pertaining to SCD in Uganda.

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