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KNOWLEDGE, ATTITUDE AND PRACTICES TOWARDS MANAGEMENT OF SICKLE CELL DISEASE AMONG CARETAKERS OF SICKLERS AT PAEDIATRIC WARD IN MBALE RRH. A CROSS-SECTIONAL STUDY.

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Abstract

Introduction:

Purpose of the study: The study aims at assessing the knowledge, attitude, and practices towards the management of sickle cell disease among caretakers of sicklers at the pediatric ward in Mbale Regional Referral Hospital.

Methods:

A cross-sectional study that employed a simple random probability sampling technique to select 100 caretakers of sicklers at the pediatric ward to participate in the study. The questionnaire method was used in the collection of data.

Results:

79(79%) of the caretakers reported pallor as a sign of SCD that requires immediate attention, 71(71%) knew blood transfusion as a treatment option for SCD, and 76(76%) knew the child should drink 10-15 glasses of water per day as a precaution to be taken at home for the child to live healthy. However, the majority of the participants 62(62%) did not know the complications of SCD if not managed well. 86(86%) preferred taking the child to a health facility when they get a sickle cell crisis, 82(82%) agreed that a child with SCD should get regular treatments and 82(82%) agreed that a child with SCD should get regular treatments. 43(43%) reported giving the child painkillers when a child gets a painful crisis and 38(38%) reported ensuring the child drinks enough water to prevent a sickle cell crisis.

Conclusions:

Given the above results, most of the respondents had good knowledge, a positive attitude, and poor practices towards the management of SCD.

Recommendations.

Health workers at Mbale regional referral pediatric unit should offer continuous health education to caretakers to improve their practices towards the management of SCD. The Ministry of Health should introduce a universal newborn screening program for early diagnosis and initiation of comprehensive SCD care for children. Caretakers should adhere to the recommended home-based care immediately after the child is diagnosed to prevent complications.

Keywords: Sickle cell disease management, Sickle cell crisis, Knowledge, Sickler, Attitude, Caretakers, Submitted: 2023-04-13 Accepted: 2023-07-29

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1. BACKGROUND OF THE STUDY.

Sickle cell disease (SCD) is a set of genetic red blood cell disorders characterized by the presence of abnormal hemoglobin in red blood cells. According to the Center of Disease Control and Prevention, healthy red blood cells are round, and they move through small blood vessels to carry oxygen to all parts of the body., In someone who has SCD, the red blood cells become hard and sticky and look like a C-shaped farm tool called a "sickle" (CDC,2023), the sickle cells die early, which causes a constant shortage of red blood cells. Also, according to the Center of Disease Control and Prevention, when they travel through small blood vessels, they get stuck and clog the blood flow(CDC,2023). This can cause pain and other serious complications (health problems) such as infection, acute chest syndrome, and stroke (CDC, 2022).

If both parents have SCT, there is a 50% chance that any child of theirs will have SCT if they inherit the sickle cell gene from one of the parents and a 25% chance that any of the children will have SCD (CDC, 2020).

Around the world, more than 90% of children with SCD do not survive to adulthood in countries with poor resources. However, more than 90% of Americans with SCD live into adulthood since the disease is detected early through newborn screening (NBS) programs. As a result, there is early access to health care and early complications are prevented. In Africa, more than half of the 1000 children born with SCD each day die before they reach 5 years old (http://sickle.cell.com/statistic s, 2020).

Comprehensive SCD care includes prompt treatment of acute events, prophylaxis against infections with oral penicillin, and vaccination against Streptococcus pneumoniae, plus prompt diagnosis and treatment of complications and educative programs provided to all individuals with SCD. (Makani *et al*., 2018).

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However, 25% of children with SCD do not receive pneumococcal vaccination, and only 33% are monitored for risk of stroke around the world (ht tp://sickle.cell.com/statistics, 2020).

A child who has sickle cell disease should be under a health provider's care but parents can do many things at home to reduce and maintain the child's health (Makani *et al*., 2018).

According to Havugarurema, 2022, Parental knowledge about SCD has a direct effect on reducing mortality and complications related to Sickle cell disease. Families of children affected by SCD face several hardships caused by raising a child afflicted with this disease. However, few studies have investigated the level of knowledge of sickle cell disease among caretakers (Havugarurema, 2020).

In a survey carried out in Eastern Uganda about knowledge practices and clinical care among patients attending SCD clinics including Mbale RRH, it was found that Regarding the management of SCD, 6.5% had heard about hydroxyurea though none were taking it personally, 42% were receiving antimalarial prophylaxis with sulphadoxine/pyrimethamine, while 51.6% were taking chloroquine and 34.4% had received the pneumococcal vaccine (Olupot-Olupot *et al*., 2020).

1.1. General objectives.

To assess the knowledge, attitude, and practices towards the management of sickle cell disease among caretakers of sicklers at the pediatric ward in Mbale Regional Referral Hospital.

1.2. Specific Objectives.

- To assess the level of knowledge about the management of sickle cell disease among caretakers of sicklers at the pediatric ward in Mbale Regional Referral Hospital.
- To determine the attitude towards the management of sickle cell disease among caretakers of sicklers at the pediatric ward in Mbale Regional Referral Hospital.
- To determine the practices towards management of sickle cell disease among caretakers

of sicklers at the pediatric ward in Mbale Regional Referral Hospital.

2. METHODOLOGY.

2.1. Study Area.

The study was carried out at Mbale Regional Referral Hospital in the pediatric ward. The hospital is located on Pallisa road in Mbale City, Eastern Uganda. It serves people from various districts such as Busia, Budaka, Kapchorwa, Bukwa, Butaleja,Manafwa,Mbale, Pallisa, Sironko and Tororo. The hospital also serves many more patients from outside the hospital's catchment area.

2.2. Study Design.

This study was a cross-sectional study, which employed quantitative data collection methods. This design was used because it facilitated the collection of adequate data despite the limited time and resources that were available for the study. Data was collected at a single point in time and there was no follow-up of the respondents.

2.3. Study Population.

The study involved caretakers of children with sickle cell disease who were seeking care at the pediatric ward of Mbale Regional Referral Hospital at the time of the study.

2.4. Sample Size Determination.

The sample size was obtained using the Kish Leslie (1965) Formulae

$$n = \frac{Z^2 P\ (1 - P)}{d^2}$$

Where; n = sample size

Z = the standard variate (normal Z-score) corresponding to the confidence interval of 95% Z=1.96

P= Prevalence=50% since the prevalence of sickle cell disease is not known.

d=acceptance error/required precision of the estimate =0.098

N=100 respondents

2.5. Sampling Technique.

The study employed a simple random probability sampling technique to select the required number of caretakers to participate in the study. This technique was used because it gave all the caretakers of children with SCD in the pediatric ward equal chances to participate in the study.

2.6. Sampling Procedure.

The researcher employed the lottery method of simple random sampling. Here, yes and no were written on small papers, folded, and mixed thoroughly in a small box. Then each caretaker of a child with SCD in the pediatric ward picked a paper from the box one at a time. Whoever picked yes participated in the study depending on the number of participants required to participate in the study.

2.7. Data Collection Method.

The study employed the questionnaire method in the collection of data because the method was simple, time-saving, and cheap as many questionnaires were administered to various respondents simultaneously. Record keeping and retrieval for future reference were also made possible.

2.8. Data Collection Tools.

A self-administered questionnaire was issued to respondents who can read and write. For illiterate respondents, the researcher administered questionnaire was conducted. The questionnaires consisted of questions addressing information regarding knowledge, attitude, and practices towards the management of sickle cell disease among caretakers of sicklers at the pediatric ward in Mbale RRH. Brief characteristics of the respondents were also obtained.

2.9. Data Collection Procedure.

Data was collected from caretakers of sicklers at the pediatric ward in Mbale RRH. The respondents were informed about the content and intent of the study and informed consent was sought. The questionnaire forms were then handed to the respondents and they were given instructions on how they were to be filled.

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For participants unable to read and write help in answering the questions was provided to them by the researcher and research assistant through thorough interpretation of the questions.

A time of collection of the questionnaires was communicated to the respondents upon filling the questionnaires, the forms were returned to the researcher. Data was collected from 5 respondents per day for 20 days making a total of 100 respondents.

2.10. Study variables.

These included the dependent and independent variables.

2.10.1. Independent variables.

The Independent variables of the study were knowledge, attitude, and practices toward the management of SCD among caretakers of sicklers at the pediatric ward in Mbale RRH.

2.10.2. Dependent variable.

The dependent variable is the management of SCD among caretakers of sicklers at the pediatric ward in Mbale RRH.

2.11. Pilot study.

A pilot study was carried out one week before the start of the actual data collection at the pediatric ward at Mbale RRH. This was relevant to assess whether the required research and information is available from the population hence ascertaining the area feasible for the study.

2.12. Quality control.

The data collection tool i.e. the questionnaire was pretested at Mbale RRH by the researcher who selected randomly a few respondents at the pediatric ward and issued the questionnaire to them. The answers were then analyzed to assess the feasibility of the tool before using it for data collection. The questionnaire was checked for errors and omissions to ensure accuracy in filling it and the necessary adjustments were made.

The researcher trained three research assistants from the hospital who helped with data collection. These were trained on how to treat respondents ethically, and how to translate any question in the questionnaires for the respondents. Ample time was also given to the respondents to allow them to provide adequate information. Data collection will be done by the researcher himself and his trained assistants.

All the above were done while adhering to the facility's rules and regulations.

2.13. Inclusion criteria.

The study included only caretakers of sicklers at the pediatric ward who were available during the data collection period and were willing to voluntarily consent to participate in the study.

2.14. Exclusion criteria.

Caretakers of non-sicklers in the pediatric ward were excluded from the study. Caretakers of sicklers in the pediatric ward who did not consent were excluded from the study.

2.15. Data Analysis and Presentation.

The data collected was analyzed using Microsoft Excel, SPSS software version 2and STATA version 13.0. Results obtained were presented in the form of frequency tables, percentage pie charts, and graphs.

2.16. Ethical Considerations.

An official letter from the Medicare Health Professionals College research committee introducing the researcher was presented to the Director of Mbale Regional Referral Hospital who then directed the researcher to the chairperson of the Mbale Regional Referral Hospital Research and ethics committee to seek permission to carry out research. The chairperson then addressed me with a letter permitting me to carry out the data collection from the respondents.

The Researcher ensured that she gets written and signed consent from the respondents and not coercing them. The confidentiality, dignity, and respect of all participants was ensured.

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Table 1: **Respondents Bio data.**

Variables	Frequency(f)	Percentage
Age range (n=100		
18-20	10	10%
21-30	33	33%
31-50	50	50%
Others	7	7%
Sex (n=100)		
Male	24	24%
Female	76	76%
Tribe (n=100)		
Mugishu	53	53%
Mugwere	38	38%
Iteso	05	05%
Others	04	04%
Religion(n=100)		
Catholic	27	27%
Moslem	25	25%
Born aain	20	20%
Anglican	24	24%
Others	04	04%
Occupation(n=100)		
Student	12	12%
Civil servant	10	10%
Peasant	42	42%
Others	36	36%
Marital status(n=100)		
Single	32	32%
Married	27	27%
Widowed	06	06%
Divorced	35	35%
Level of education (n=100)		
Primary	28	28%
Secondary	36	36%
University	24	24%
No formal education	12	12%

3. STUDY FINDING.

According to Table 1, half of the respondents 50(50%) were between the age bracket of (31-50) years while a few 7 (7%) fell among others. The majority 76(66%) of the respondents were female and 24(24%) males participated in the study. By tribe, 53(53%) respondents were Bagishu while a few 4(4%) fell among others. Most of the respondents 27(27%) were Catholics, and the least 4(4%) were among others. The majority of the respondents 42(42%) fell into others while the minority 10(10%) were Civil servants. Majority of the respondents 35(35%) were divorced, whereas 6(6%) were widowed. As per the education level of the respondents, 40(40%) were of Secondary level, while 5(5%) were university graduates.

3.1. *Knowledge towards management of SCD.*

Figure 1 shows that majority of the participants 90(90%) had ever heard about SCD yet minority10(10%) had never heard about SCD.

Table 2 shows that the majority of the participants 79(79%) reported pallor as the sign of SCD which requires immediate attention yet minority of the participants 10 (10%) able to mention fever.

Table 3 shows that the majority of the participants 76(76%) knew the child should drink 10-15 glasses of water per day as a precaution to be taken at home in order for the child to live healthy yet minority 04(04%) knew they had to make sure child avoids strenuous activity in order to live healthy.

Table 4 shows that the majority of the participants 71(71%) knew blood transfusion as treatment option for SCD while none of the respondents did not know any treatment option used in the management of SCD .

Figure 2 shows that the majority of the participants 62(62%) did not know the complications of SCD if not managed well yet the minority of the respondents 11(11%) knew renal failure as one of the complications o SCD if not managed well.

3.2. *Attitude towards management of SCD.*

Table 5 shows that the majority of the respondents 86(86%) preferred taking the child to a health facility yet none mentioned another option they preferred when a child gets a sickle cell crisis.

Figure 3 shows that the majority of the respondents 82(82%) agreed that a child with SCD should get regular treatments yet the minority of the respondents 18(18%) disagreed that a child should get regular treatments.

Figure 4 shows that the majority of the respondents 76(76%) believed that SCD complications can be prevented yet the minority 24(24%)did not believe that SCD complications can be prevented.

Figure 5 shows that the majority of the respondents 85(85%) thought that testing for SCD in the newborn period is important while the minority of the respondents 15(15%) did not think it important.

3.3. *Practices towards management of SCD.*

Table 6 shows that the majority of the respondents 43(43%) reported giving the child pain killers while minority of the respondents 13(13%) reported placing warm towels on the affected part when a child gets a painful crisis.

Table 7 shows that the majority of the respondents 38(38%) reported ensuring the child drinks enough water in order to prevent a sickle cell crisis while minority of the respondents 10(10%) fell among others.

4. DISCUSSION.

4.1. *Level of Knowledge towards management of SCD.*

This study revealed that the majority of the participants 79(79%) knew pallor as a sign in children with SCD that requires immediate attention. These findings indicate that the respondents are capable of identifying when a child requires immediate management. This is probably because this is the sign most children with SCD present with for management. The findings agree with the findings of a study that was conducted in India by Kacha and others in 2020 which showed 75% of the respondents knew pallor as the sign of SCD. This correspondence in results could be because both studies were conducted among caretakers of children with SCD.

The study revealed that the majority of the caretakers 76(76%) knew the child should drink 10-15 glasses of water per day as the precautions that should be taken at home for the child to live healthy. These findings indicate that the respondents had a good level of knowledge of management of the children with SCD. This is probably due to adequate sensitization of the caretakers about SCD and the health workers who attend to the children during clinic days. These findings agree with the findings of a study that was conducted in India by Kacha and others in 2020 which found that 81.55% of the respondents knew their child should drink 10-15 glasses of water per day.

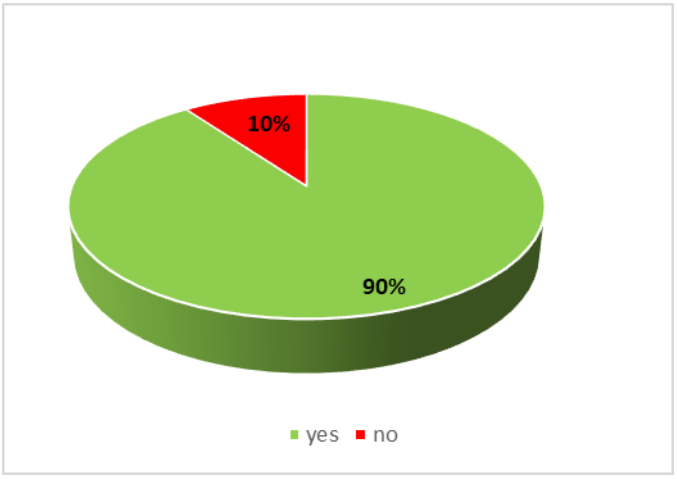

Figure 1: **Distribution of respondents by whether they had ever heard about SCD. (n=100)**

Table 2: **Distribution of respondents by their knowledge of the signs of SCD that require immediate attention. (n=100)**

Response	Frequency	Percentage
Pallor	79	79%
Fever	10	10%
Joint pains	11	11%

Table 3: **Distribution of respondents by their knowledge of the precautions that should be taken at home in order for the child to live healthy. (n=100)**

Response	Frequency	Percentage
Child should drink 10-15 glasses of water per day.	76	76%
Child should avoid of high altitude	05	05%
Provide regular folic acid to child	15	15%
Make sure child avoids strenuous activity	04	04%

Table 4: **Distribution of respondents by their knowledge of the treatment options used in the management of SCD. (n=100)**

Response	Frequency	Percentage
Hydroxyurea	05	05%
Folic acid	24	24%
Blood transfusion	71	71%
Don't know	0	0%

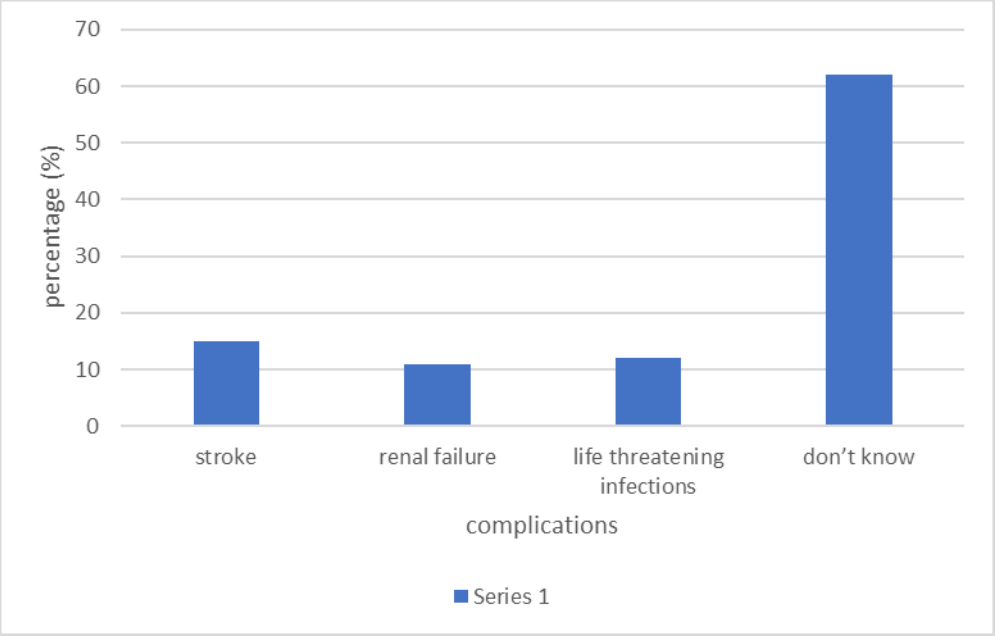

Figure 2: **Distribution of respondents by their knowledge of the complications of SCD if a child is not managed well.**

Table 5: **Distribution of respondents by the management option they prefer when a child gets a sickle cell crisis. (n=100)**

Response	Frequency	Percentage
Take the child to a health facility	86	86%
Self-medication	08	08%
Herbal medicine	06	06%
Others	0	0%

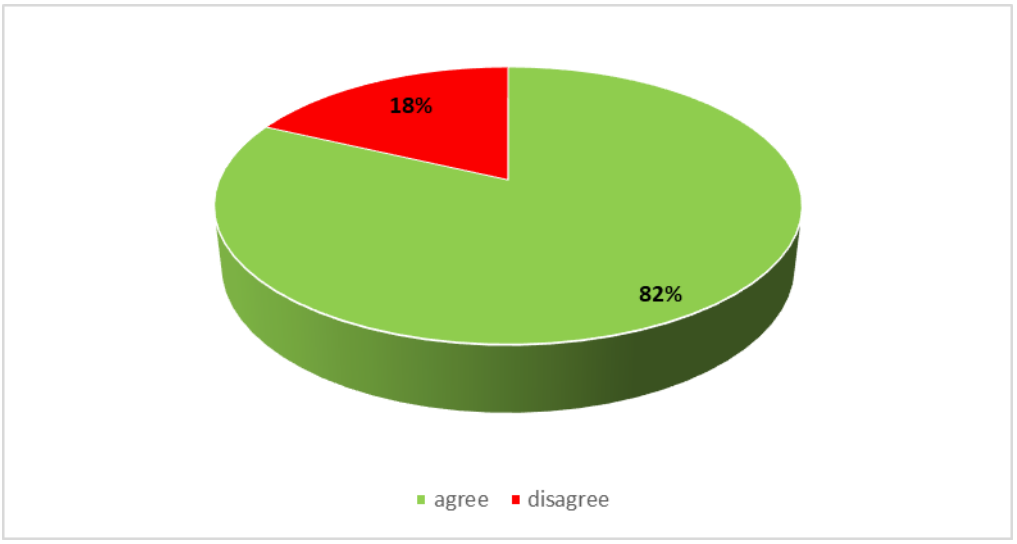

Figure 3: **Distribution of respondents by whether they agree that a child with SCD should get regular treatments (n=100)**

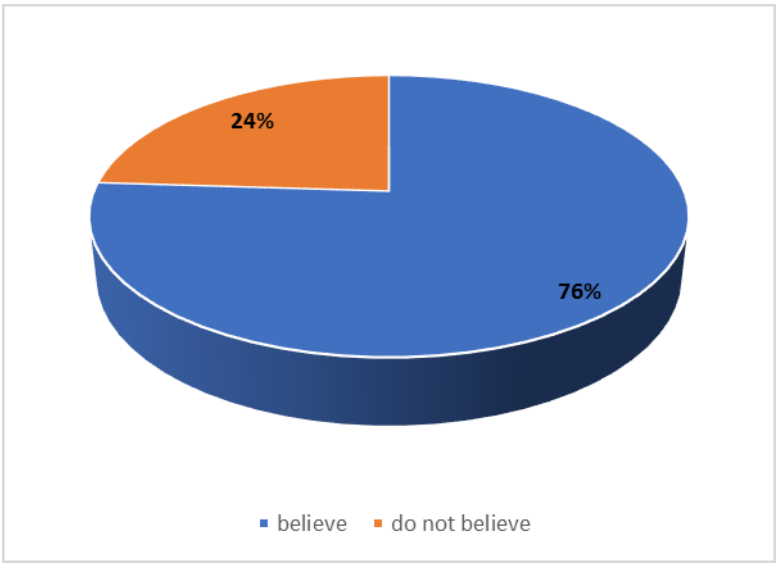

Figure 4: **Distribution of respondents by whether they believe that SCD complications can be prevented. (n=100)**

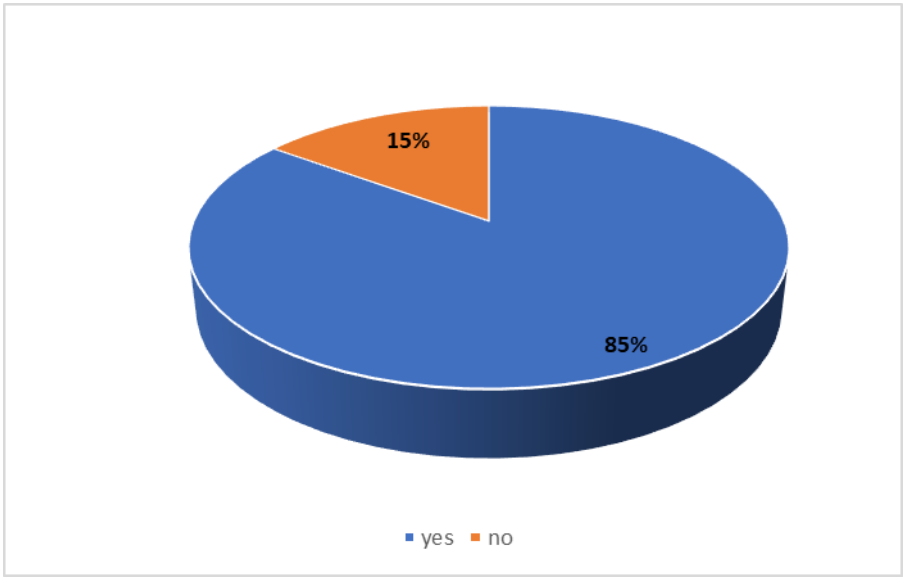

Figure 5: **Distribution of respondents by whether they think testing for SCD is important in the new born is important. (n=100)**

Table 6: **Distribution of respondents by what they do when a child gets a painful crisis. (n=100)**

Response	Frequency	Percentage
Give the child pain killers	43	43%
Massage the affected part	18	18%
Place warm towels on the affected part	13	13%
Others	26	26%

Table 7: **Distribution of respondents by what they do to prevent sickle cell crisis. (n=100)**

Response	Frequency	Percentage
Ensuring the child drinks enough water	38	38%
Ensuring the child takes healthy food that prevents anaemia	35	35%
Ensuring the child avoids extreme weather	17	17%
others	10	10%

This study revealed that the majority of the participants knew the treatments used in the management of SCD as 71(71%) knew blood transfusion as a treatment option in the management of SCD, followed by Folic acid 24(24%) and Hydroxyurea 05(05%). These findings show that the respondents had a good level of knowledge of the treatments used in the management of SCD. These findings could be because most of the children on the ward presented with anaemia and were receiving a blood transfusion and all respondents were taking care of children with SCD. These findings agree with the findings of a study that was carried out in Rwanda Havugarurema in 2020 which revealed that the majority of caretakers were able to mention blood transfusion as an important treatment for sickle cell and another study in Uganda by Olupot-Olupot and others in 2020 which revealed that only 6.5% knew Hydroxyurea.

This study revealed that the majority of the participants 62(62%) did not know the complications of SCD if not managed well, 15% knew stroke followed by infections12 (12%) and then renal failure 11(11%). These findings indicate that the respondents had a poor level of knowledge of the complications of SCD if not managed well. This is probably because most participants had only one child with SCD and so were not well experienced with the consequences of poor management. However, these findings disagree with the findings of a study that was done in Saudi Arabia by Alghamdi and others in 2018 which found that 74.5% knew the complications of SCD. This difference in results could be because of the difference in the study populations where the studies were conducted.

4.2. Attitude towards management of SCD.

This study revealed that the majority of the respondents 86(86%) preferred taking the child to a health facility, 08 (08%) self-medicated and 06(06%) administered traditional treatment when a child gets a sickle cell crisis. This shows that the respondents have a positive attitude toward the management of SCD in a health facility. This is probably due to the existence of free treatment and the nearness of the health facility. These findings slightly agree with the findings of a study that was conducted in Congo by Okoko and others in 2017 which revealed that during a vaso-occlusive crisis, (64.8%) of parents preferred a health facility, 20.7% self-medicated and (14.5%) administered traditional treatment.

The study showed that the majority of the respondents 82(82%) agreed that a child with SCD should get regular treatments. This indicates that the respondents have a positive attitude toward the management of SCD. This could be due to adequate health education on adherence to regular treatments provided by the health workers during clinic days. These findings slightly agree with the findings of a study that was carried out in India by Kacha and others in 2020 which revealed that 78.6% of the respondents agreed that there is a need to take regular treatments by their child with SCA.

Furthermore, the study revealed the majority of the respondents 76(76%) believed that SCD complications can be prevented through proper management. This indicates that respondents had a positive attitude towards the prevention of the complications of SCD. This could be due to the availability of accessible sickle cell care services at hospital. These findings agree with the findings of a study that was done in Tanzania by Suleimani

in 2020 which revealed that 70% of respondents had a positive attitude towards the prevention of SCD complications.

The study revealed that the majority of the respondents 85(85%) thought that testing for SCD in the newborn period is important. The findings indicate that respondents had a high attitude towards the management of SCD. This could be because the majority know that diagnosing a child with SCD early facilitates early management thereby reducing the mortality rate of children with SCD. However, there is no evidence of a study conducted among caretakers of sicklers about whether testing for SCD in the newborn period is important.

4.3. Practices towards management of SCD.

Data analysis and interpretation revealed the following major finding under this objective. This study revealed that less than a half of the respondents 43(43%) reported giving the child painkillers, followed by 26 (26%) who fell among others,18(18 %) who reported massaging the affected part while 13(13%) reported placing warm towels over the affected part when a child gets a painful crisis. The findings indicate that respondents do not adhere to the recommended practices when a child gets a painful crisis. These findings could be because of majority prefer taking a child to a health facility in case of a crisis. The findings disagree with the findings of a study in Congo done by Okoko and others in 2017 which revealed that 72.1% mentioned administering painkillers, 70.9% mentioned providing massages, and 18.5% mentioned applying hot towels over the affected part of their children as the therapeutics provided at home when a child gets a painful crisis.

The findings show that only 38(38%) of the respondents reported ensuring the child drinks enough water to prevent a sickle cell crisis, 35(35%)mentioned ensuring the child takes healthy food that prevents anaemia and 17(17%) mentioned ensuring the child avoids extreme weather. This indicates that the majority of the caretakers take precautions to prevent sickle cell crisis in their children. This could be due to limited care given to their sick children as a result of limited time as they spend most of their time working for a living. These findings disagree with the findings of a study done in India by Ajinkpang and others, in 2022 in Ghana which revealed that most caretakers ensured that the children took enough water, took healthy food that prevented anemia, protected children from infections like malaria which can be a precipitating factor for crises and reduced exposure to extremes of weather.

5. CONCLUSIONS.

This study specifically sought to determine the knowledge, attitude, and practices towards the management of sickle cell disease among caretakers of sicklers at the pediatric ward in Mbale Regional Referral Hospital.

Regarding knowledge towards the management of SCD, this study established that the majority of the respondents had a good level of knowledge of the signs and symptoms of sickle cell disease that require immediate attention, majority knew the precautions that should be taken at home for the child to live healthily and the various treatments used in the management of SCD. However, only a few of the respondents knew the complications of SCD if not managed well.

Furthermore, this study established that the majority of the respondents preferred taking the child to a health facility in case the child gets a sickle cell crisis, the majority agreed that a child with SCD should get regular treatments, the majority believed that SCD complications can be prevented through proper management and the majority thought that testing for SCD in the newborn period is important.

However, the study established that only a few of the respondents were doing the recommended practices when a child gets a painful crisis and for prevention of a sickle cell crisis.

Given these findings, most of the respondents had good knowledge, a positive attitude, and poor practices towards the management of SCD.

6. STUDY LIMITATIONS.

The researcher also encountered difficulty in getting the required information from the respondents as some caretakers feared opening up to give the needed information.

7. RECOMMENDATIONS.

Health workers at Mbale regional referral pediatric unit should offer continuous health education to caretakers to improve their practices towards the management of SCD. The Ministry of Health should introduce a universal newborn screening program for early diagnosis and initiation of comprehensive SCD care. Caretakers should adhere to the recommended home-based care immediately after the child is diagnosed to prevent complications.

8. ACKNOWLEDGEMENT.

I thank the almighty God who has been with me in all corners of my life up to the time of this research study.

I extend great thanks to my supervisor who has ensured that my research report comes to the best.

Special thanks go to the staff and patients at Mbale Regional Referral Hospital for their support and encouragement in the production of this work.

I also thank the entire staff of Medicare Health Professionals College for the support and effort rendered to me through this course of study.

9. ABBREVIATIONS AND ACRONYMS.

CDC- Centers for Disease Control and prevention
Hb- Haemoglobin
NBS- New Born Screening
PMGC- Premarital Genetic Counselling
RRH- Regional Referral Hospital
SCA- Sickle Cell Anaemia
SCD- Sickle Cell Disease
SCT- Sickle Cell Trait
WHO- World Health Organization

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