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# Knowledge, attitude, and practices toward sickle cell management among caregivers of Children below five years attending Rakai general hospital, Rakai district. A cross-sectional study.

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## Abstract.

### Background.

Uganda lacks enough resources to support the increasing incidences of sickle cell disease (SCD), as the management of these children increases the Government expenditure. This study assessed knowledge, attitude, and practices towards sickle cell management among caretakers of children below five years attending Rakai general hospital, Rakai district.

### Methodology:

The study employed a descriptive cross-sectional study design using a simple random sampling technique. Data was collected from 50 respondents using a semi-structured questionnaire. Analysis was done using the Excel computer program and presented in tables and figures, then interpreted.

### Results:

(40%) Of the children were between 3-4 years, (50%) of caretakers had attained secondary level education, 94% of the participants had ever heard about the sickle cell disease, 56% fairly knew the signs, and 50% knew it was inherited from the parents. Respondents had a good attitude towards the management of sickle cell disease, as 60% of them noted that screening of children for sickle cell disease is very important, and 85% of the respondents believed that children with sickle cell disease should go to school. Respondents had fair control practices of sickle cell crises among these children since 58% of them used conventional medicine from the hospital, and 43% gave painkillers to their children when they experienced pain.

### Conclusively.

Even though knowledge, attitude, and practices toward sickle cell management among care takers of children below five years were generally fair, the study established gaps regarding the practices of care takers and also a proportion still use herbal medicine as treatment.

### Recommendation.

The management of Rakai general hospital aims to increase the ongoing education and orientation of health workers to equip them with knowledge on the management of sickle cell disease.

***Keywords:*** *Sickle cell disease, Caretakers, Under-five children, Knowledge on Sickle cell management, Pediatric care, Rakai General Hospital, Rakai District*
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## Background.

Sickle cell disease is a group of inherited disorders caused by mutations in HBB, which encodes the hemoglobin subunit β. This abnormal sickle shape of erythrocytes disrupts blood flow in blood vessels called vaso-occlusion, which leads to ischemia of distal tissues and inflammation with symptoms defining an acute pain crisis. (The lancet Global health, 2018). Between 2000 and 2021, national incidence rates of sickle cell disease were relatively stable. Still, total births of babies with sickle cell disease increased globally by 13·7% (95% uncertainty interval 11·1–16·5), to 515 000 (425 000–614 000), primarily due to population growth in the Caribbean and western and central sub-Saharan Africa. The number of people living with sickle cell disease globally increased by 41·4% (38·3–44·9), from 5·46 million (4·62–6·45) in 2000 to 7·74 million (6·51–9·2) in 2021 (Azalea M Thompson, 2023).

A critical review of sickle cell disease burden in sub-Saharan Africa revealed that 85.5% of % geographical distribution of sickle cell among children is in West Africa and 9.1% in central Africa. In Nigeria, an overview of sickle cell disease from the social demographic triangle among children revealed that a total of 138 newly diagnosed SCD patients aged 7months to 41 years made up 61% of the children seen out of the consecutive patients screened in the study period. About 98.555% and 1.4% were homozygous sickle cell hemoglobin (SS) and heterozygous sickle cell c

(SC) variants, respectively. The pediatric department recorded the highest proportion of SCD, which was 65%.

In Uganda, a surveillance study was carried out, and it revealed that 0·7% of the children had sickle cell disease and ranged from 0·2% in the South Western region to 1·5% in the East Central region. Sickle cell trait was found in all 112 districts. Those in the South Western region had the lowest prevalence, being less than 5% in nine and less than 3% in two. Eight districts had prevalence greater than 20%, with the highest being 23·9% in Alebtong.

According to a report presented in the parliament of Uganda, out of the 20,000-25,000 babies born with sickle cell disease in Uganda 70%-80% die before 5 years of age and it contributes to 15% of under 5 mortality rate which is at 64/1000 live births (Blog.dhsprogramme.com)and Uganda lacks enough resources to support the increasing incidences of sickle cell disease(SCD) as the management of these children increases the Government expenditure which neglects other sectors that would rather be concentrated on other sectors.

The information obtained from the Hospital records of Rakai general hospitals shows that an average of 120 children are admitted every week secondary to sickle cell crisis, and these are exacerbated by infections like malaria and dehydration, which are preventable. About 10% of these children die due to complications of sickle cell disease. Care takers spend a lot of time in the hospital, which wastes a lot of time and money spent on these children, which ends up affecting their income and hence lowers their standard of living. This study assessed knowledge, attitude, and practices towards sickle cell management among caretakers of children below five years attending Rakai general hospital, Rakai district.

## Methodology.

### Study design.

The study was conducted through a sectional study design on caregivers attending the sickle cell clinic. The information concerning the objectives was collected using formulated questionnaires. The design was chosen because it captures all the information to describe the research problem, and it was convenient for both subjects and the researcher.

### Study Area.

The study was conducted in Rakai General Hospital, which has several departments, including the pediatric department, operating theatre, male and female medical and surgical wards, Antenatal and Labor ward, ART and TB clinic, about 198.7km from Kampala in Rakai district, on the pediatric ward for children with sickle cell disease. It is a Government Hospital that treats people of all conditions, including sickle cell, around the district and receives about 500 people in a day.

### Study population.

The study was conducted on caregivers who had visited Rakai General Hospital for their routine medical checkup at the sickle cell clinic, suffering from sickle cell disease in Rakai General Hospital, Rakai district.

### Sample size determination.

The sample of the study was obtained from this population by a random sampling method.

The sample size will be determined using Burton's formula (1965) as follows;

S=(QR) /O Where;

S=required sample size

Q = Number of days the researcher takes while collecting data

R = Maximum number of people per day

O = O = Maximum time the interviewer spends on each participant

Therefore,

R=5respondents

Q=5days

O=1/2hours

QR/O=5x5/1/2

25x2=50respondents

Therefore, the researcher used 50 respondents.

### Sampling technique.

The study employed a simple random procedure to select the sample. This involves selecting a sample without bias from the target population, and it ensures each candidate has an equal chance of being chosen.

### Sampling procedure.

The caretakers were randomly selected from all the caretakers bringing their children to the sickle cell clinic in Rakai General Hospital, Rakai district.

### Data collection method.

The data was collected using a questionnaire because it is cheap and there is data accuracy.

### Data collection tool.

The data was collected using the formulated open-ended questionnaires written in the English language and later translated into the local language (Luganda) for respondents who were not able to comprehend or interpret the questions.

### Data Collection Procedure.

The letter was first obtained from Kampala School of Health Sciences seeking permission to be granted to Rakai General Hospital. Then, the acceptance letter was received from Rakai General Hospital, and consent was obtained from patients by voluntary signing of the consent form. Then, information was obtained from caretakers by using a random sampling technique.

### Study variables.
The dependent variable was the management of sickle cell disease in children below 5years
The independent variable was the knowledge, attitude, and practices towards sickle cell disease.

### Quality control.
The quality of the research was ensured by employing strategies that dealt with the threats of validity, like the appropriate use of the study design and use of piloting the study to pretest the instruments to be used, like the questionnaires to be used in the collection of data, by giving adequate time in data collection, and results from the pretest met the standard.

### Pretest the collection tools.
The questionnaires used in data collection were pretested first to help determine if respondents understand the questions, as well as if they can perform tasks or have the information the questionnaire requires.
This was conducted at the paediatric ward of the hospital on about 10% of the sample.

### Data analysis and presentation.
Data was analyzed manually and involved summarizing key findings, explanations, and analysis of data according to the study objectives, and was presented in frequency distribution tables, graphs, and pie charts.

### Ethical approval.
The permission to carry out research was granted by Kampala School of Health Sciences, and a consent form was presented and signed by every respondent before collecting data from the respondents. The interviews were conducted privately, and respondents were assured that their information would be strictly kept confidential. The principle of autonomy was practiced, whereby all the participants received enough information about the study, and this enabled them to exercise their rights during decision-making on whether to participate or not, and caregivers were thanked for their contribution.

### Informed consent
Respondents were assured of maximum confidentiality, and only numbers instead of names were used to identify the respondents. The study only commenced after the objectives of the study had been well explained to participants and they had consented to participate in the study.

## Results.
### Social demographic characteristics.

**Table 1: Shows the distribution of respondents according to their social demographic characteristics (N=50).**

| Variables | Frequency(f) | Percentage (%) |
|---|---|---|
| **Age range of the child** | | |
| 1-6months | 09 | 18 |
| 6-12months | 16 | 32 |
| 1-3years | 05 | 10 |
| 3-4years | 20 | 40 |
| **Total** | **50** | **100** |
| **Sex of the child** | | |
| Male | 31 | 62 |
| Female | 19 | 38 |
| **Total** | **50** | **100** |
| **Religion of the child** | | |
| Anglican | 22 | 44 |
| Moslem | 15 | 30 |
| Catholic | 11 | 22 |
| Others | 02 | 04 |
| **Total** | **50** | **100** |
| **Caregiver's level of education** | 16 | 32 |
| Primary | 25 | 50 |
| Secondary | 09 | 18 |
| Tertiary | 00 | 00 |
| Others | **50** | **100** |
| **Total** | | |

| | | |
|---|---|---|
| **Relationship with the child** | 25 | 50 |
| Mother | 02 | 04 |
| Father | 15 | 30 |
| Grandparent | 08 | 16 |
| Others | **50** | **100** |
| **Total** | | |

According to Table 1, 40% of the children were between 3-4 years, while 10% of them were between 1-3 years of age. The majority of the children were male (62%), and a minority (38%) were female. By religion, almost half (44%) were Anglicans, whereas the least (4%) fell in the category of others, like Seventh-day Adventists. Half of the respondents (50%) attained secondary level education, whereas the least (18%) attained tertiary level of education. Half of the caretakers (50%) were mothers, whereas the least (4%) were fathers to the children.

## Knowledge of sickle cell management among caregivers of children below five years

**Figure 1: shows the distribution of respondents according to whether they have ever heard about sickle cell disease (N=50).**

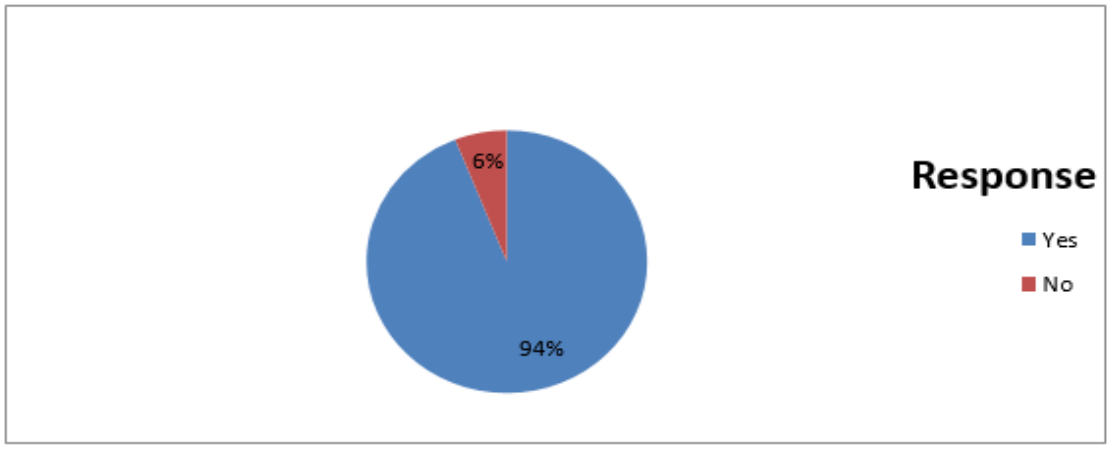


Figure 1, almost all the respondents (94%) had ever heard about sickle cell disease, and the least (6%) had never heard about the disease.

**Figure 2: shows distribution of respondents according to where they heard sickle cell disease from (N=50)**

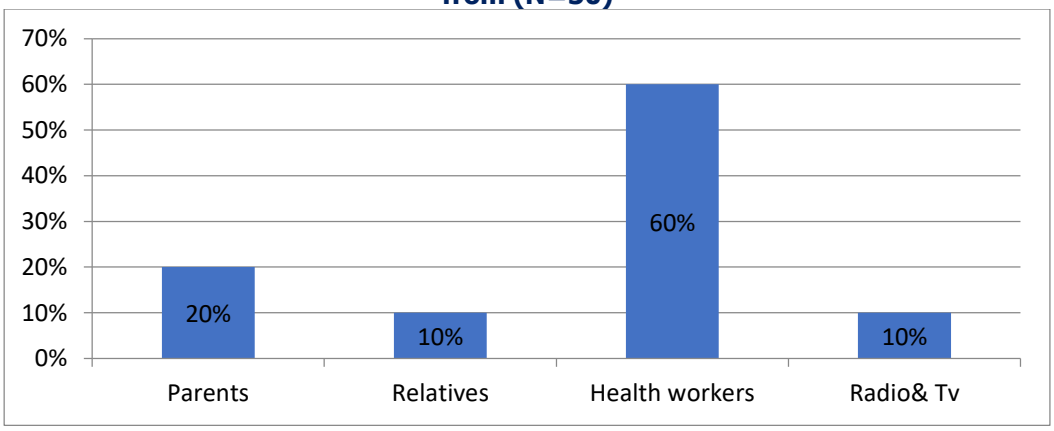

Figure 2 shows that more than half of the respondents (60%) heard about sickle cell disease from the health workers, whereas the least (10%) heard about it from relatives, and the radio and TV.

**Table 2: Shows the distribution of respondents according to their knowledge about how sickle cell disease is acquired (N=50)**



| Response | Frequency(f) | Percentage (%) |
|---|---|---|
| Inherited | 24 | 48 |
| Contact with an infected person | 05 | 10 |
| Insect bite | 03 | 06 |
| I don't know | 16 | 32 |
| Others specify | 02 | 04 |
| **Total** | **50** | **100** |

Table 2, almost half (40%) of the respondents did not know the causes of sickle cell disease, whereas the least (6%) of them mentioned that it is caused by annoying evil spirits, and it is a curse from the gods.

**Figure 3: Shows the distribution of respondents by their knowledge about how Sickle cell disease is diagnosed (N=50).**

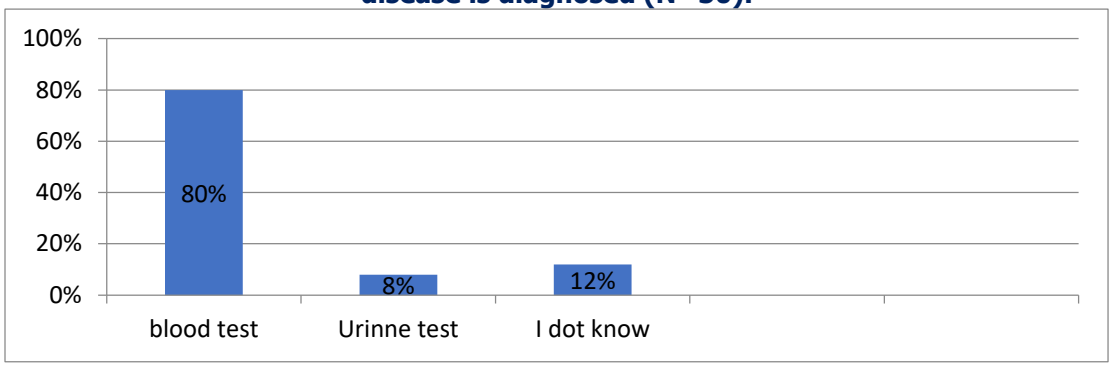


Figure 3 shows that, majority (80%) of the respondents knew that sickle cell is diagnosed by blood tests cures whereas a minority (8%) knew that a urine test is the diagnostic test for sickle cell disease.

**Table 3: Shows distribution of respondents according to their knowledge about the signs of SCD that require immediate attention (N=50).**

| Response | Frequency(f) | Percentage (%) |
|---|---|---|
| Pallor | 34 | 68 |
| Fever | 10 | 20 |
| Joint pains | 04 | 08 |
| Others (specify) | 02 | 04 |
| **Total** | **50** | **100** |

Table 3 indicates that more than half of the respondents (56%) knew pallor was a sign of sickle cell disease, whereas the least (4%) did not know any signs of sickle cell disease.

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**Figure 4: Shows distribution of respondents according to their knowledge on the treatment of sickle cell disease (N=50).**

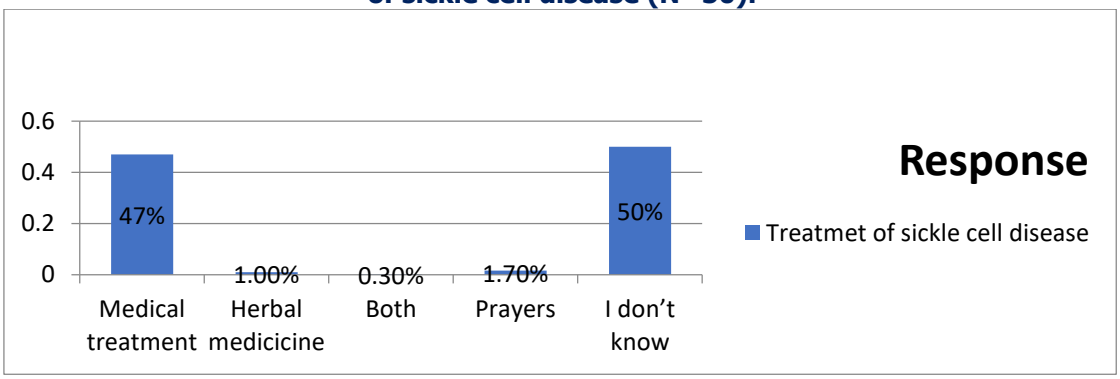


Figure 4 shows that half (50%) of the respondents did not know the treatment of sickle cell disease, whereas the least (0.3%) knew that both medical and herbal treatments are used.

**Figure 5: shows the distribution of respondents according to their knowledge of whether sickle cell disease can be cured. (N=50).**

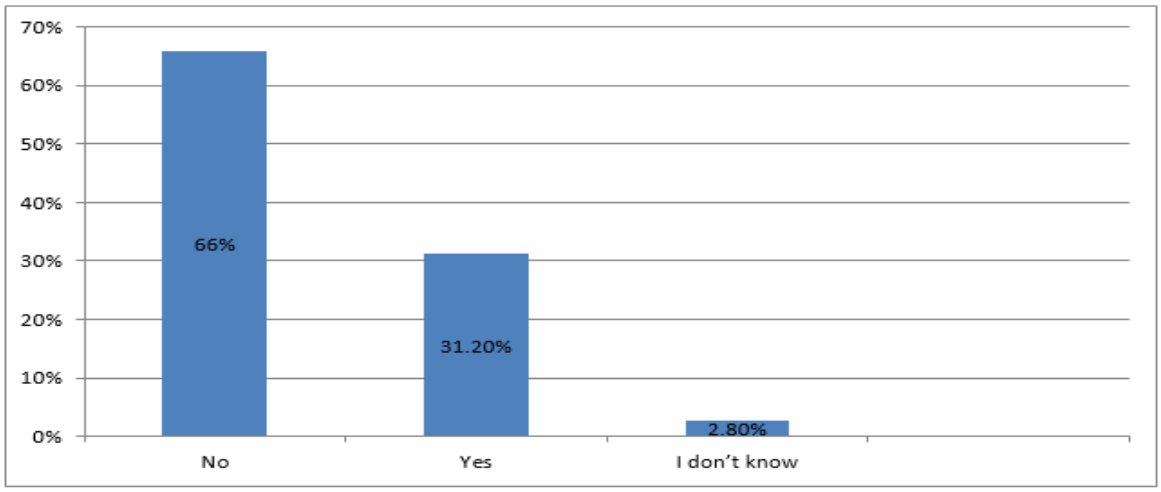


Figure 5 shows that, majority (66%) of the respondents know that Sickle cell disease has no cure, whereas the minority (2.8%) did not know whether it can be cured or not.

## Attitude toward sickle cell management among caretakers of children below five years.

**Table 4: Distribution of respondents according to whether they think newborn testing for sickle cell disease is important (N=50)**

| Response | Frequency(f) | Percentage (%) |
|---|---|---|
| Very important | 30 | 60 |
| Important | 15 | 30 |
| Not important | 05 | 10 |
| **Total** | **50** | **100** |

Table 4 shows that more than half (60%) of the respondents thought that testing for Sickle cell disease in the newborn period is very important, whereas the least (10%) thought that it is not important to test the newborns for Sickle cell disease.

**Table 5: Distribution of respondents by how they find taking care of children below five years with sickle cell disease (N=50).**



| Response | Frequency (f) | Percentage (%) |
|---|---|---|
| Comfortable | 10 | 20 |
| Difficult and stressful | 17 | 34 |
| Easy | 20 | 40 |
| Bearable | 3 | 6 |
| **Total** | **50** | **100** |

Table 5 shows that (40%) of the caregivers found it easy to take care of children with sickle cell disease, while only (6%) found it bearable to take care of these children.

**Figure 6: Distribution of respondents according to whether they think children should go to school. (N=50).**

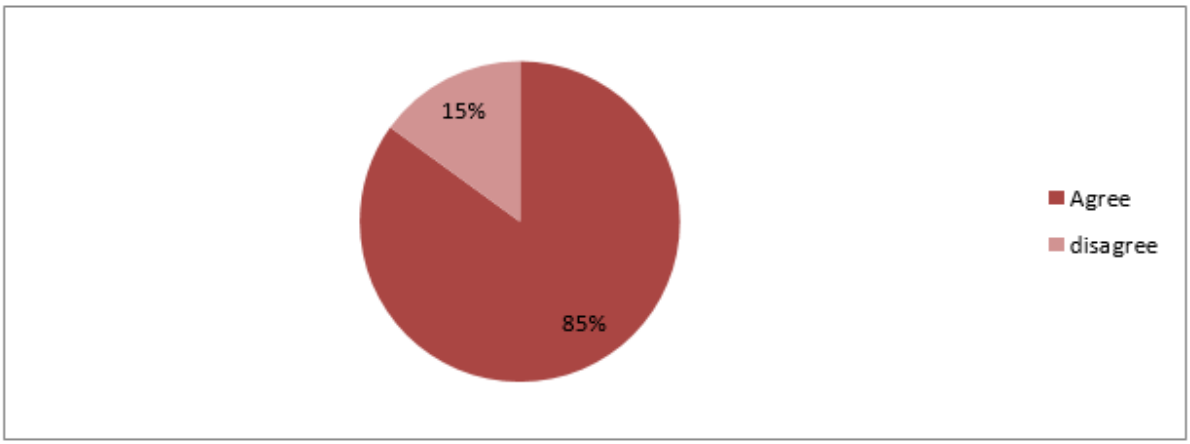


Figure 6 indicates that, majority of the respondents (85%) thought that these children should also go to school where whereas the least (15%) thought these children didn't need to attend school.

**Figure 7: Distribution of respondents according to whether they wish a child with sickle cell disease should die. (N=50).**

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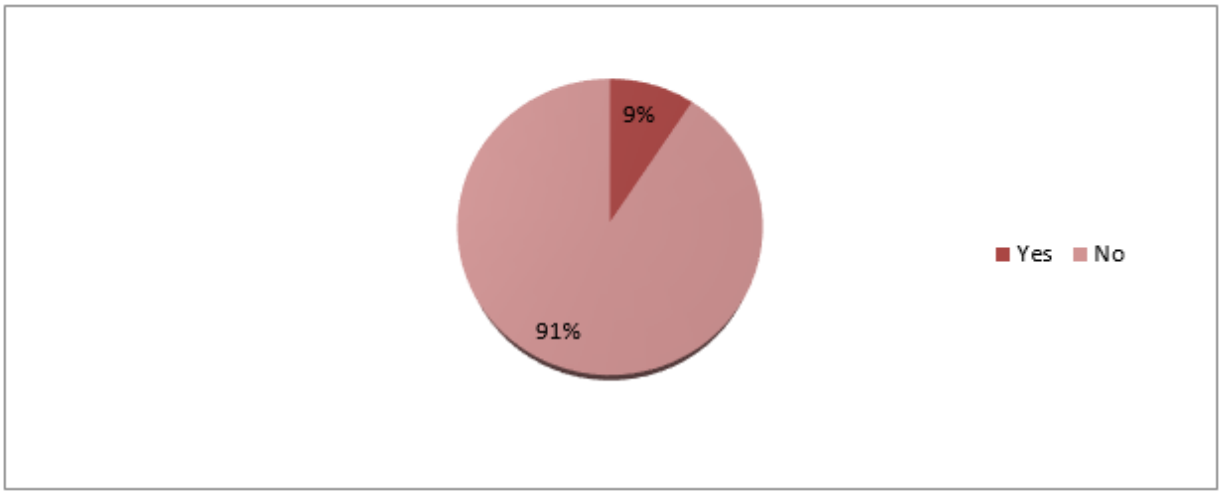


Figure 7 shows that almost all the respondents (90%) loved being with their children despite their condition, whereas the least (10%) of them wished for them to die.

**Figure 8: Distribution of respondents by whether they think poor management can lead to complications then death (N=50).**

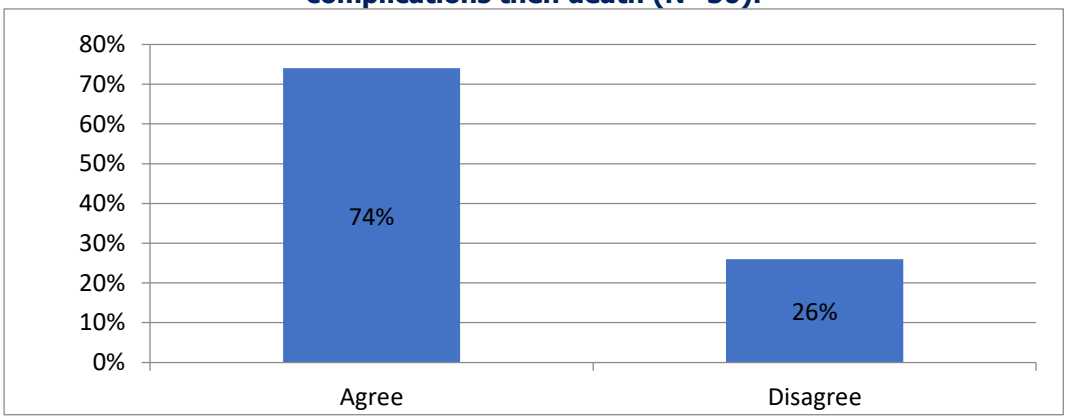


Figure 8 shows that the majority (74%) of the respondents agreed that poor management can cause the death of the child, whereas the minority (26%) did not agree with this.

## Practices toward sickle cell management among caregivers of children below five years.

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**Figure 9: Shows the distribution of respondents according to the type of management option they use (N=50).**

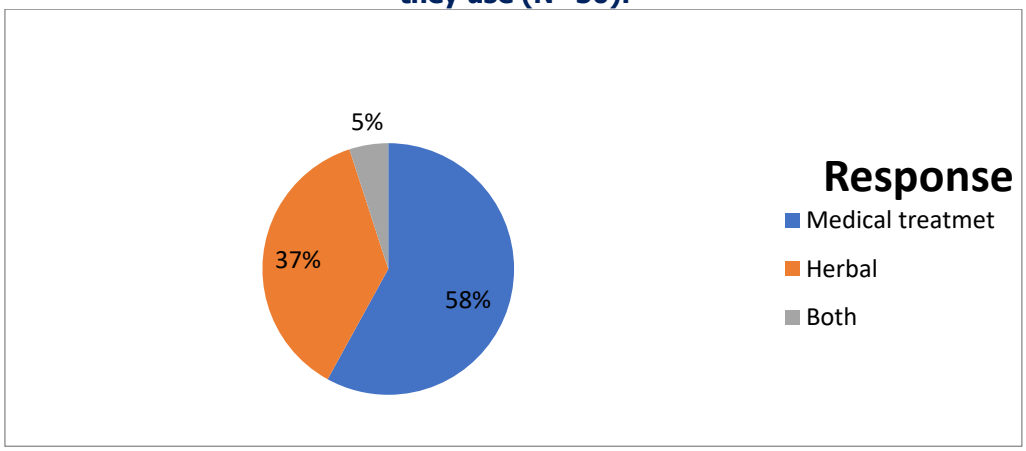


Figure 9 shows that more than half of the respondents (58%) use medical treatment in the management of their children, whereas the least (5%) use both medical and herbal medication.

**Table 6: Shows the distribution of caregivers according to what they do if the child experiences pain (N=50).**

| Response | Frequency (f) | Percentage (%) |
|---|---|---|
| Pain killer | 22 | 44 |
| Massage the affected part | 9 | 18 |
| Put a warm cloth | 13 | 26 |
| Others | 6 | 12 |
| **Total** | **50** | **100** |

Table 6 shows that almost half (44%) of the respondents use painkillers when a child experiences pain, while the least (12%) do other practices to stop the pain.

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**Figure 10: Shows the distribution of caregivers according to how often the child sleeps under a treated mosquito net (N=50).**



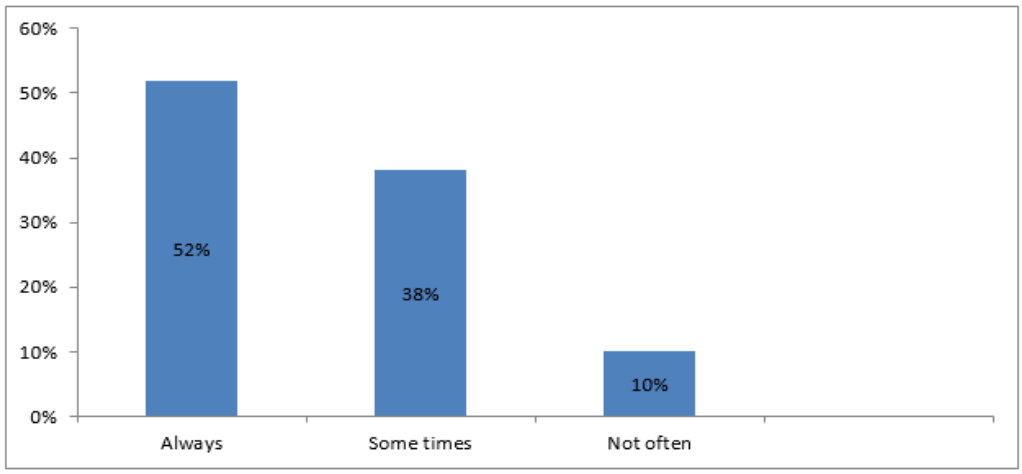


Figure 10 indicates that more than half (52%) of the respondents make sure their child sleeps under treated mosquito nets, whereas the least (10%) do not sleep under a mosquito net.

**Table 7: Shows the distribution of respondents according to how they feed their children with sickle cell disease (N=50).**

| Response | Frequency (f) | Percentage (%) |
|---|---|---|
| Balanced diet | 13 | 26% |
| Just like the rest | 31 | 62% |
| More fruits | 6 | 12% |
| **Total** | **50** | **100** |

Table 7 shows that more than half (62%) of the respondents feed their children with sickle cell, just like the rest of the children, while the minority (12%) feed their children more on fruits.

**Figure 11: shows the distribution of respondents according to how many times they give their children water (N=50%)**

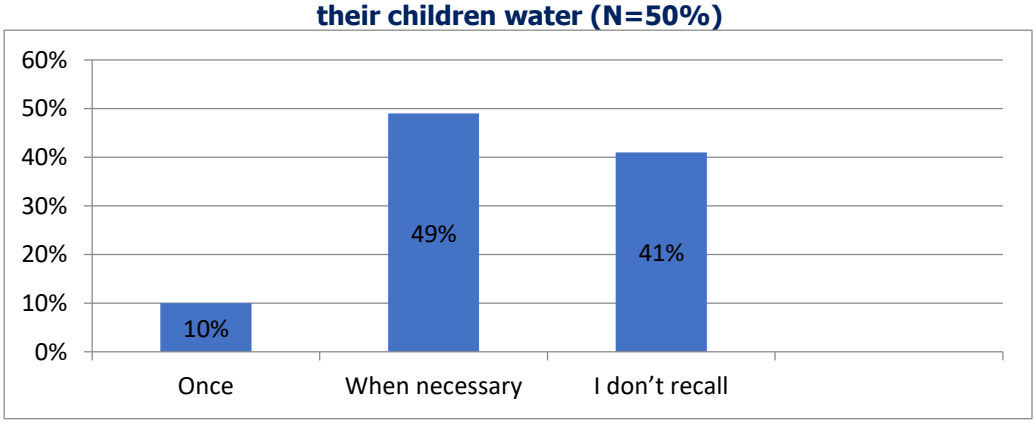

Figure 11 shows that almost half (49%) of the respondents only give their children water when necessary, whereas the least (10%) only give their children water once a day.

**Figure 12: shows the distribution of respondents according to how many times the medication of the child is over (N=50).**



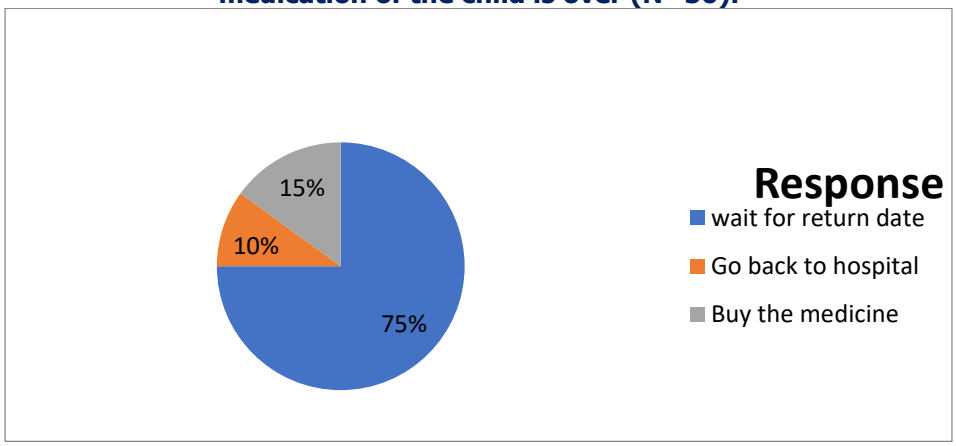


Figure 12 shows that the majority (75%) of the respondents wait for the return date when the medication given to their children is over, as the minority (10%) go back to the hospital and meet the health worker.

## Discussion.

### Knowledge toward sickle cell management among caregivers of children below 5 years of age.

Findings obtained from a sample of 50 participants showed that (94%) had ever had sickle cell disease. This is an implication that the community has been sensitized due to the presence of sicklers. And this is in line with a study by Adewoyin (2015), where 98.4% had ever heard about it.

Additionally, more than half (60%) of the respondents had heard about it from the health workers, and this indicates that these caregivers often visit the hospitals due to their sick children.

Furthermore, half of the respondents (50%) knew that sickle cell disease is acquired by inheritance, which was the right answer, and 32% did not know the cause, despite the high awareness of the disease; these people had inadequate knowledge of its cause.

The study further revealed that the majority (80%) of the respondents knew that Sickle cell disease is diagnosed by blood tests, and this large number is attributed to the screening and tests that were done to their children before they were declared sicklers. The results were consistent with Gordon Djan (2018), where (79.9%) of the respondents knew that blood tests are used in the diagnosis of Sickle cell disease.

Given the study findings, the majority of the respondents (68%) knew that pallor is one of the signs seen in a child with sickle cell, which indicates that caregivers knew when the child needed immediate help from the health workers. Findings don't fall far from Deborah Namajja (2023), where (70%) of the respondents agreed on pallor as a critical sign.

Half (50%)of the respondents did not know the recommended treatment for a child with sickle cell disease, and this is attributed to a lot of false information and myths from the community and inadequate sensitization. This goes in line with Nketsiah James ( 2022), whose study revealed that 49.3% of the respondents did not know the treatment for the disease.

Conclusively, the study revealed that more than half (66%) of the respondents knew that sickle cell disease can never be cured, and they added that if a child is born with sickle cell disease, their chances of not becoming adults are minimal because that disease does not have a definite treatment.

### Attitude toward sickle cell disease management among caregivers of children below five years.

The study discovered that the majority (60%) of the respondents agreed that screening of newborn children for sickle cell disease is very important, and this may be due to having children with sickle cells, and they realized the importance of early screening. This goes slightly in line with a study by Ahmed A. Daak (2016), where 73.1% of the respondents agreed to the screening of sickle cell.

Furthermore, the study discovered that almost half (40%) of the respondents found it easy to take care of the children with sickle cell disease, and this is attributed to the fact that they love taking care of their children regardless of the condition. The findings are in line with a study by Arch G Mios III (2015), where 39.5% of physicians (care takers) found it easy to care for the children.

In addition to the above, the study discovered that (85% )of the respondents strongly concluded that children with sickle

cell disease should also go to school like other children, and this may be due to the benefits of education that they have also noticed in these children. These results are in conjunction with the results from research by James Nketiah Brown (2022), where (84.5%) of the respondents agreed to taking children to school.

Conclusively, about the attitude of caregivers toward sickle cell management, the study revealed that almost all (91%) of the respondents loved their children and never wished them to die because they still loved taking care of and staying with their children despite the illness they had. This goes in line with

## Practices toward sickle cell management among caregivers of children below five years.

With reference to the study findings, 58% of the respondents used medical treatment from the hospital, and this indicates that caregivers were trying to get medical treatment for their children. This agrees with Consiliate Apolot (2023), where (58.3%) of the respondents used conventional medicine in managing their children.

Additionally, when the respondents were asked about what they do when a child experiences a crisis, almost half (44%) of the respondents reported giving their children painkillers to stop the pain they experience. This indicated the bad practice of self-medication without consultation from health workers; these findings agreed with Deborah Namajja (2023), in which 43% of the respondents gave their children painkillers when they got pain.

Given the study findings, more than half (52%) of the respondents consistently ensured that their children slept under treated mosquito nets. This indicates that they were trying to prevent malaria, which precipitates anaemia and, in the end, causes a crisis. These findings are consistent with Musonda (2023), whose study revealed that 50% of the respondents ensured their children slept under mosquito nets.

## Conclusion.

The study about knowledge, attitude, and practices toward sickle cell management among care takers of children below five years established that the study participants portrayed high awareness (94%) of the disease, with pleasingly fair knowledge about the causes of sickle cell disease (48%), signs 68%), and how sickle cell disease is diagnosed (66%). However, despite the high awareness, the respondents still lacked knowledge about the management of the disease, as half (50%) did not know the management options for the disease.

The respondents had a good attitude towards the management of sickle cell disease, given 60% thought newborn screening is very important, 40% found it easy to take care of these children, 85% agreed on taking them to school, and finally, almost all of them (91%) disagreed with their children dying.

It was also noted that the respondents have poor control and management practices of sickle cell crises as almost half (44%) of the respondents use pain killers when a child experiences pain from home, (49%) only ensure giving these children water, more than half (52%) made sure children sleep under treated mosquito nets and (58%) of them used conventional medicine.

It was concluded that, despite the high awareness and good attitude, the study established gaps regarding the practices of caregivers, as it was seen that only 16% were consistent with mosquito nets, and also a proportion still use herbal medicine as treatment and do not emphasize water intake.

## Recommendations.

The Ministry of Health should ensure that it carries out enough sensitization about screening for the sickle cell disease and also knowledge on the management of the disease, and this will also help improve the caregivers' attitude towards its management. It should also ensure enough supply and use of mosquito nets for all citizens. Conclusively, the Ministry of Health should teach the caregivers of sicklers good health practices, such as drinking water, to prevent frequent crises.

The administration of Rakai General Hospital should put more emphasis on health talks in the hospital and the nearby community about the management of sickle cell disease among caregivers of sicklers, and also equip these parents with knowledge on how to prevent and manage the crises in sickle cell children.

The management of Rakai general hospital aims to increase the ongoing education and orientation of health workers to equip them with knowledge on the management of sickle cell disease, so that they can use this knowledge in the sensitization of the population about the management and care of children with sickle cell disease.

The Health workers at Rakai General Hospital should attend more CMIs about the management of children below five years of age with sickle cell disease.

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## List of Abbreviations

**DDHO :** District Director of Health Office
**HM:** Herbal Medicine
**KSHS:** Kampala School of Health Sciences
**NGOs:** Non-governmental Organizations
**RBCs:** Red blood cells
**RGH:** Rakai General Hospital
**SCD:** Sickle cell disease
**UNICEF:** United Nations Children's Fund
**WHO:** World Health Organization
**TB:** Tuberculosis
**ART:** Anti-retroviral therapy

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Data used in this study are available upon request from the corresponding author.

## Author's contribution
FN designed the study, conducted data collection, cleaned and analyzed data, drafted the manuscript, and SN supervised all stages of the study from conceptualization of the topic to manuscript writing.

## Author's biography.
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