Factors Contributing to Low Utilization of Sickle Cell Services among Care givers of Children with Sickle Cell Disease at Dr Ambrosoli Memorial Hospital Kalongo, Agago District. A Descriptive Cross-sectional Study.

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Abstract

Background:
Sickle Cell Disease (SCD) is a genetically inherited disease that results in the hemoglobin becoming sickle-shaped in the presence of little oxygen. Utilization of sickle cell services has remained poor despite the discoveries of the screening tests, and the different ways of management, yet the burden of sickle cell is on the rise day by day here in Uganda. The purpose of this study, therefore, was to determine factors contributing to the low utilization of sickle cell services by the caregivers of children with SCD in Dr. Ambrosoli memorial hospital, Kalongo.

Objectives:
This study was to determine the factors contributing to the low utilization of sickle cell services among the caregivers of children with SCD.

Methodology:
The study employed Quantitative **(**Researcher-administered structured questionnaires) for the caregivers and qualitative (Key informants) i.e the medical staff in the Paediatric ward and OPD sickle cell clinic. SPSS version 23.0 statistical software was used to generate descriptive statistics. All the information was coded and assigned to the study variables.

Results:
Results showed high utilization of sickle cell services among caregivers of children with SCD. This is the impact of knowledge about the disease, free services offered, being aware of the sickle cell services offered, negligible side effects of the medications given, good community perceptions about the sickle cell services offered, and good attitudes of health workers when delivering the services.

Conclusions:
It was found that there is high utilization of sickle cell services among the caregivers, and some factors affect the utilization positively while others negatively.

Recommendations: Further research should be conducted to specifically determine the factors contributing to low utilization of Preconception sickle cell screening, to promote prevention rather than management of SCD.

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1 Background

Sickle Cell Disease (SCD) is the major genetic condition burdening the people of Northern Uganda. The most common structural mutation of normal adult haemoglobin (HbA) is Sickle haemoglobin (HbS). It is inherited as a Mendelian trait i.e heterozygous carriers who inherit one HbS allele and one HbA allele are usually asymptomatic. However, homozygous carriers who inherit HbS alleles from both parents suffer from SCD, which often results in intermittent vaso-occlusive crisis, followed by tissue ischaemia, acute and chronic pain, and organ damage (Al-Azri *et al.*, 2016).

The world health organization (WHO) and the United Nations General Assembly recognize SCD as a universal public health problem due to the morbidity and mortality caused by the disease and the significant social and economic impact that results (UN General Assembly, 2009).

Globally, about 5% of the population and over 7% of pregnant women are carriers of haemoglobin disorders like SCD (Modell & Darlison, 2008). According to WHO, about 240 million people are heterozygous for inherited haemoglobinopathies, including thalassemia and SCD (Elfattah et al., 2015). Elsewhere, 20–25 million people are affected by SCD (Aygun & Odame, 2012). Also, 275,000 out of the 330,000 babies born worldwide with major haemoglobinopathy have SCD. (Modell & Darlison, 2008).

In Africa, there are 12-15million of the world's total population of those suffering from SCD (Aygun & Odame, 2012). It is estimated that 240,000 children are born with SCD in developing countries like Sub-Saharan Africa according to Makani *et al.,* (2011), and 50–80% of those die before the age of 5 years (high childhood mortality) majorly because of infectious complications and severe anaemia (Aygun & Odame, 2012).

In Uganda, though statistics are not clear, at least 20, 000 babies are born with SCD per year (Ndeezi *et al.,* 2016). Between February 2014, and March 2015, 99, 243 dried blood spots were analyzed and results were available for 97,631. Sickle cell trait was seen in all districts, meaning it is a general burden in Uganda. The overall number of children with sickle cell trait was 12 979 (13·3%) and with the disease was 716 (0·7%). The prevalence of SCT is 1.3% in Mid-Northern Uganda. The lowest prevalence was less than 3·0% in two districts. Eight districts had a prevalence greater than 20·0%, with the highest being Alebtong with 23·9% (Ndeezi *et al.,* 2016).

The affected children suffer poor standard of living with frequent hospitalization. Some of them drop out of school or are not taken to school at all. Their parents' productivity is equally reduced as they frequently attend to their hospitalized children and spend money on hospital bills. The country also wastes income on purchasing treatment for SCD, decreasing the national economy. These effects will continually be experienced if sickle cell services are not properly utilized (Mulumba & Wilson, 2015).

If not properly managed, SCD causes the death of children, and the victims constantly undergo pain from vaso-occlusion, and their education is affected due to frequent hospitalization. The parents and relatives of such children always have to attend to them when hospitalized, increasing their expenses yet decreasing their productivity, and part of the country's income is spent on purchasing treatment for SCD (Mulumba & Wilson, 2015).

The most relevant management approach to SCD is utilizing the Sickle cell services especially sickle cell screening, counseling, and adhering to treatment (Hussein *et al.,* 2018). The WHO 2006 identified a variety of medical genetic screening programs that could help to reduce the incidences of SCD and are appropriate for low and middle-income countries (WHO, 2006). Those programs are; carrier identification using family pedigrees and screening tests, and postnatal screening for sickle cell disorders (Mulumba & Wilson, 2015).

Despite all the advances made towards reducing the burden of SCD through the provision of Sickle Cell services, its utilization remained poor day by day, increasing the burden of SCD (Uganda: Sickle Cells Disease On the Rise in Uganda | Ministry of Health Knowledge Management Portal, n.d.). So far, the barriers to offering sickle cell counseling by health practitioners, and the knowledge and attitudes of women towards its utilization, have been studied (B.Sc Nursing Student, National Medical College Nursing Campus, Birgunj, Nepal. et al., 2017) (Holtkamp *et al.,* 2017). However, the studies made involved different populations, time frames, and geographical locations. Therefore, this study aimed to identify the factors contributing to the low utilization of sickle cell services among caregivers of

children with SCD at Dr.Ambrosoli Memorial Hospital.

2 Methodology

Study Design

This study design was a descriptive cross-sectional, employing a mixed method of data collection and analysis. A cross-sectional study is where the investigator measures the outcome and exposures of the study participants at the same time (Setia, 2016). This design was used since it is less expensive and requires a relatively short time to conduct.

Study Site / Setting

This study was conducted in Dr.Ambrosoli memorial hospital kalongo, Agago district, in Northern Uganda. Dr.Ambrosoli memorial hospital is situated in the heart of kalongo town council, Mission ward,Oret Parish kalongo town,Agago North County,Agago district.

The study setting was Paediatric ward and OPD sickle cell clinic of Dr.Ambrosoli memorial hospital. The sickle cell clinic operates during the day and offers sickle cell services to children with SCD through their caregivers. These services include prophylactic treatment of anemia with folic acid, counseling, screening, and diagnosis of SCD, e.t.c (Uganda Clinical Guidelines 2016_FINAL.pdf, n.d.).

Pediatric ward operates both day and night accommodating children with different medical conditions, including but not limited to SCD, malaria, pneumonia, diarrhea, e.t.c. Services offered include Routine monitoring of vital signs (Pulse, Temperature, Blood Pressure, and Respiratory rate), management of various complications through medications and intravenous fluids, e.t.c (Uganda Clinical Guidelines 2016_FINAL.pdf, n.d.).

Study populations

All the caregivers of children with SCD attend services at the OPD sickle cell clinic and Paediatric ward in Dr.Ambrosoli memorial hospital. As well as the qualified medical staff in the sickle cell clinic and paediatric ward. On average, monthly 122 and 51 children with SCD and their caregivers attend OPD sickle cell clinic and paediatric ward services respectively at Dr.Ambrosoli memorial hospital (Dr. Ambrosoli mem. Hosp. records, 2021).

Sample size determination

This study benefited from Kish & Leslie, (1965) formula of sample size determination, which is as follows.

Number (n) =

Where;

n= the estimated sample size

Z = is a 95% confidence interval, on a standard normal distribution.

p= the prevalence of SCT in Northern Uganda (18.6%) (Northern Uganda tops sickle cell trait prevalence, 2014).

q= the proportion of children without SCT (81.4%)

δ = the percentage error to be committed, which is 5%

Z=1.96, p= 186, q= 0 814, δ =0 05

n = (1.96) 2x0.186x0.814

(0.05) 2

n =233.

Adjusting the sample size

Where n is the reduced sample size, N=173 (the population size), and no=233 (the original sample size).

Therefore, n=100 But the researcher increased the sample size by 5% to cater for errors. Thus, the actual sample size was 105.

Meaning, that the researcher selected 105 participants for quantitative and purposively selected qualified medical staff for qualitative study until saturation level of information was achieved (6 medical staff).

Sampling technique

Probability-based Sampling

A systematic random sampling technique was used, i.e the nth person was picked to participate in the study based on the calculated interval. From nth=

Since the average total monthly number of caretakers attending to their children with SCD at the Paediatric ward and Sickle cell clinic is 173 according to hospital records, and the sample size is 105;

Then nth = = 1.67, approximately 2. Therefore, the sampling interval was 2.

To come up with the first participant, the researcher wrote numbers 1 and 2 on separate similar papers, mixed then closed eyes while picking one of them. If 1 was picked, then the first participant was the first to meet the caretaker of a child with SCD. If figure 2 was picked, then the second met caretaker of a child with SCD became the first participant. Systematic random sampling was used because it is easy to use and free from bias.

Non- probability-based sampling.

Judgemental/Purposive Sampling of qualified medical staff (including the Ward in charge) irrespective of their gender, from OPD sickle cell clinic and paediatric ward based on their ability to provide information on hospital-based factors contributing to low utilization of sickle cell services. The number of medical staff to be sampled depended on the saturation point of the information being given (6 medical staff were sampled).

Eligibility criteria (inclusion & exclusion)

Inclusion criteria

The mentally sound, and physically able caregivers of children with SCD attend services at the OPD sickle cell clinic and Paediatric ward in Dr. Ambrosoli memorial hospital.

The qualified medical staff working in those wards.

Exclusion criteria:

All those with psychosis, the blind, the deaf, and the uncooperative caregivers of children with SCD, attending services at the sickle cell clinic and Paediatric ward in Dr. Ambrosoli memorial hospital were excluded.

The unqualified medical staff working in those wards.

Study Procedure

After approval by the Institution Research and Ethics committee of Kampala school of health sciences, the researcher moved to the field and sought permission from administrators of Dr. Ambrosoli memorial hospital, who then introduced the researcher to the respective ward in charge, from whose wards the study was conducted. After permission was granted by the respective ward in charge, consent was obtained from the study population, and data was collected.

Data management

Data collection methods and instruments

Quantitative:

This study used the questionnaires structured in the English language, which were verbally translated to Acholi to cater to even the non-literate participants. The researcher asked individual participants the closed-ended questions from a questionnaire and ticked them according to the responses given by each participant. This was because most of the participants were unable to read, comprehend and write. Closed-ended questionnaires were used so that the responses of participants were guided.

Qualitative:

The method was Key informant interviews with the use of interview guides for the qualified medical staff in paediatric ward and sickle cell clinic irrespective of their gender to provide information on hospital-based factors contributing to the low utilization of sickle cell services.

Data entry & cleaning

Data were edited during and after leaving the respondents. This was done to ensure uniformity, consistency, legibility, and comprehensibility. Quantitative data were entered and cleaned using SPSS software. Data from key informants was typed in MS Word and each interview was saved in a separate file.

3 Data analysis:

Quantitative data: SPSS version 23.0 statistical software was used to generate descriptive statistics. All the information was coded and assigned to the study variables. Then, frequency and percentages were presented in tables, and a graph to show the factors affecting the utilization of Sickle Cell Services. Statistical significance was said to be achieved when the P-value was <0.05.

Qualitative data: The researcher used thematic content analysis to analyze the collected qualitative data. Then transcribed the recorded audio information during the interview into words, created themes and subthemes accordingly, coded the data for easy categorization, sorted the data accordingly, summarized and synthesized the categorized data, and finally analyzed the data.

Measurement of Variables

Dependent variables**:** The dependent variable was the utilization of sickle cell services among the caregivers of children with SCD in Dr. Ambrosoli memorial hospital. A tick in the YES box signified that had ever utilized the sickle cell services while a tick in the NO box, signified that had never utilized the sickle cell services. Therefore, 60% for yes signified high utilization, while below 60% showed low utilization.

Independent variables: These included the different factors like Client-based (lack of knowledge, unaware e.t.c), hospital-based (limited resources, inadequate staff knowledge, e.t.c), and Community-based (stigma, inaccessibility e.t.c). They were measured depending on the responses from the questionnaires on the client-based, community-based

and hospital-based factors contributing to low utilization of sickle cell services and responses from the key informants about the hospital-based factors. More than 60% of TICKS in an affirmative way signified Knowledgeable, awareness, and utilizing the sickle cell services, and vice versa. A home more than 5km was far from the hospital.

Quality Control

Validity

For the instruments to be used, the researcher availed their drafts to the supervisor who checked on the ambiguity of questions, language, content, relevancy, and comprehensiveness and appropriately made corrections. The researcher then collected data by themself to ensure that data was correctly collected thus ensuring validity.

Reliability

A study tool was pretested in the Paediatric ward at Dr. Ambrosoli memorial hospital with 11 researcher-administered questionnaires to clients and 2 qualified medical staff taken as key informants so that necessary corrections could be made.

Ethical considerations

Approval: The study was first approved by the Institution Research and Ethics Committee, Kampala school of health sciences, then Dr. Ambrosoli memorial hospital administrators introduced the researcher to the charges of OPD SCC and Paed ward.

Consent: Informed consent was sought from all the people who were selected to participate in the study. They were told the relevance of the study in reducing the burden of SCD. The participants were also told their participation was voluntary and risk-free and had a right to decline from the study at any point during the study without any punishment.

Privacy: Interviews were done from a place where the respondent found and agreed to be safe and comfortable for him or without any interruption, and not in the open or public places.

Confidentiality: The identifiers like names, the actual place of residence, and phone numbers were not used in the questionnaires. The information got in the field was coded not to allow the identification of the participants.

4 Presentation and analysis of findings

5 Response Rate

The sample size for this study was 105 for the quantitative and approximately 6 health workers for the qualitative part. The researcher created a very good rapport with the respondents, assured them of their confidentiality, and explained thoroughly the importance of their responses. As a result, all the 105 respondents and 6 health workers were achieved. Therefore on calculation, the response rate for this study was 100%.

Socio-Demographic Characteristics

The modal age bracket was 25 to 34 years, and the majority of the respondents were females (83.8%) with 70% having attained only basic education. Those married were 90.5%. The key informants interviewed consisted of male and female clinical officers and nurses aged between 30 and 40 years.

Utilization of Sickle Cell Services

It indicates that the majority (63.46%) of the caregivers of children with sickle cell disease had ever utilized the sickle cell services like screening, treatment, and health education from the hospital and were keeping the return dates given by the health care workers, while a minority (36.54%) were not. Similarly, key informant interviews revealed high utilization of sickle cell services by the caregivers of children with SCD.

"There is generally fine utilization of Sickle Cell Services because most caregivers of children with SCD do not miss appointment dates". (Said Key informant B).

Nonetheless, another viewpoint indicates that some caregivers still don't adhere to the appointment dates.

"However for other caregivers when treatment is given to the child and there is an improvement, they think healing has occurred and they miss the appointment dates, only to return when another complication has surfaced on their child", said Key informant B.

Client-based Factors contributing to low utilization of sickle cell services

From the results below, the majority of caregivers of children with sickle cell disease are knowledgeable (100%) and aware (95.2%) about the disease. A total of 95.2% said the services are free and 73.3% declined fear of side effects.

Knowledge

The respondents revealed having 100% knowledge of SCD. Contrary, key informant interviews

Table 1. Shows Socio-demographic characteristics of the Quantitative study population

VARIABLE	FFREUENCY	PERCENTAGES
AGE		
Above 45	8	7.6
35-45	28	26.7
25-34	54	51.4
15-24	15	14.3
Total	105	100
GENDER		
Female	88	83.8
Male	17	16.2
Total	105	100
EDUCATION LEVEL		
Uneducated	11	10.5
Tertiary Institution	5	4.8
Secondary	19	18.1
Primary	70	66.7
Total	105	100
MARITAL STATUS		
Widowed	3	2.9
Divorced	3	2.9
Single	4	3.8
Married	95	90.5
Total	105	100

(Source: data from respondents March 2022)

showed a lack of knowledge about SCD among caregivers of children with SCD.

"Many caregivers of children with SCD do not understand SCD, because others still think their children have been bewitched and also cannot manage sickle cell crisis like severe joint pains", said Key informant A.

Awareness

A total of 95.2% of respondents were highly aware of sickle cell services, whereas 4.8% had low awareness about those services. Similarly, key informant interviews revealed sound awareness among caregivers of children with SCD about the presence of sickle cell services.

"Even though we do not carry out community awareness, most caregivers of children with SCD who come to the health facility say they heard about Sickle cell services from the community i.e. from friends and health workers", said key informant E.

Cost of services

The majority (95.2%) of the respondents said sickle cell services are free of charge, while a minority (4.8%) talked of the high cost of services. Likely, key informant interviews showed the absence of payment for sickle cell services.

"We don't need any money and nor do we need anything, but just you to accept and come to utilize the sickle cell services," said key informant C.

Fear of side effects

Most of the respondents (73.3%) said their children do not experience any significant side effects after medication. Similarly, key informant interviews revealed that medications given possess minimal side effects.

"We give folic acid and paracetamol for pain relief, all of which have light side effects", said key informant A.

Community-based factors contributing to low utilization of sickle cell services among caregivers of children with sickle cell disease.

Generally, the results show that most caregivers of children with sickle cell disease stay far away (79%) from the health facility and are afraid of a social stigma (77.1%) from the community. In addition, a total of 93.3% of the community members have good perceptions of the sickle cell services offered.

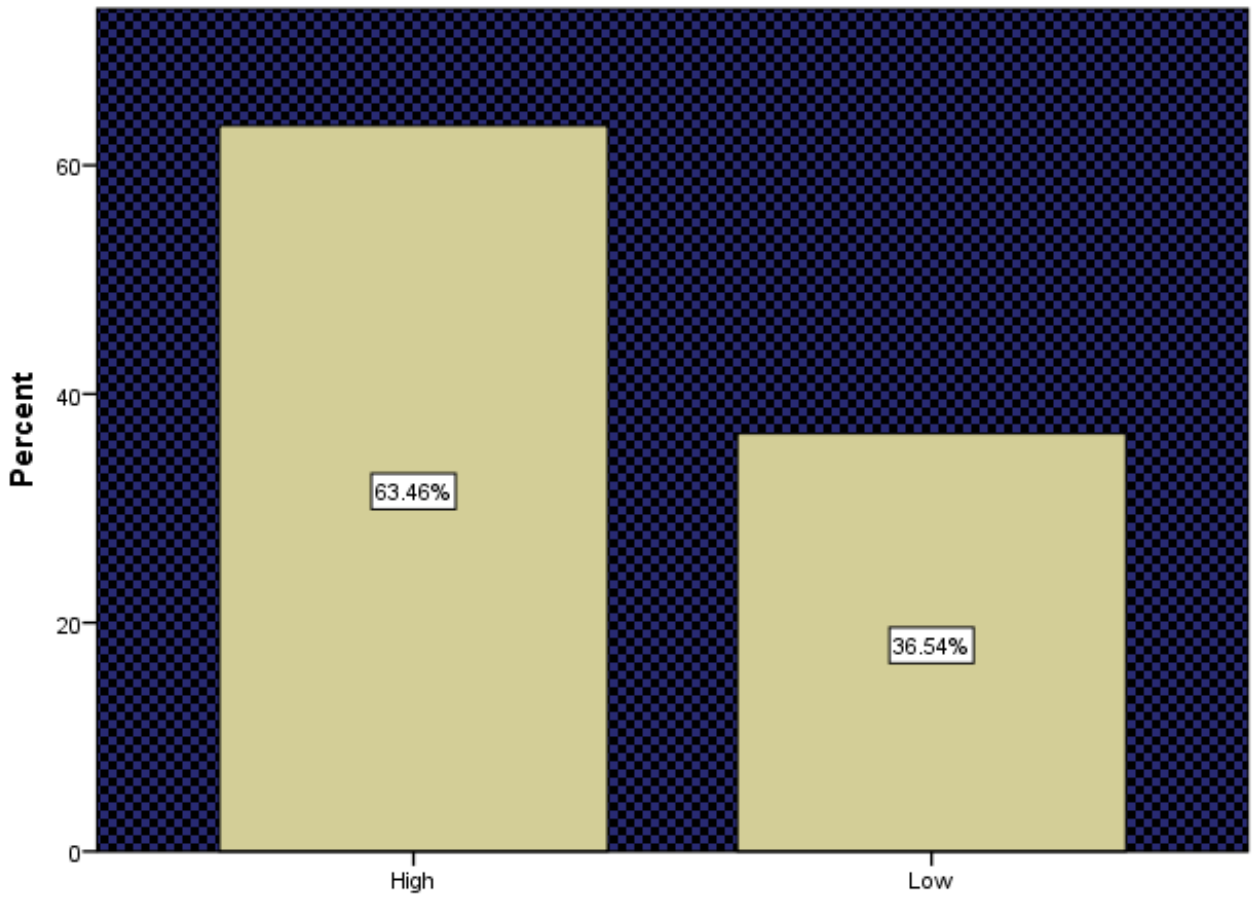

Figure 1. A bar-graph showing level of Utilization of Sickle Cell Services among the caregivers of children with sickle cell disease. (Source: data from respondents March 2022)

Also, a total of 81% of the respondents said the community members highly prioritize screening for SCD, while 19% said there is low community prioritization of screening for SCD. Contrary to the quantitative results, key informant interviews revealed not prioritizing screening for the SCD.

"Most community members do not come to screen for SCD but only come when their child is showing symptoms of the disease", said Key informant D.

Hospital-based factors contributing to low utilization of sickle cell services among caregivers of children with sickle cell disease.

The results indicate that there is an inadequacy of hospital resources like medications, and hospital conditions such as time spent at the facility being too long for the caregivers. However, the staffs have good knowledge and skills as well as work with a good attitude.

Adequacy of resources

The majority (90.5%) of respondents revealed inadequate hospital resources, while a minority (8.5%) said sometimes drugs and screening reagents are available. Similarly, key informant interviews showed inadequate resources to provide quality sickle cell services.

"We have a shortage of drugs and sometimes screening reagents run out of stock", said Key informant A.

Knowledge and skills of health workers

A total of 87.6% of respondents showed high knowledge and skills of health workers, while 11.4% talked of low knowledge among the medical staff. Likewise, key informant interviews revealed high knowledge of health workers on SCD.

"SCD is an abnormality of Red Blood Cells (RBCs), where they adopt an abnormal sickled shape which makes them useless to the body. Those cells are de-

Table 2. Shows results of client-based factors

VARIABLE	FREQUENCY	PERCENTAGES
CLIENT-BASED FACTORS		
Knowledge		
High	105	100
Low	0	0
Total	105	100
Awareness		
High	100	95.2
Low	5	4.8
Total	105	100
Cost of Services		
High	5	4.8
Free	100	95.2
Total	105	100
Fear of Side Effects		
YES	14	13.3
NO	77	73.3
Not sure	12	11.4
Total	103	98.1
Missing	2	1.9
Total	105	100

(Source: data from respondents March, 2022)

Table 3. Shows results of Community-based Factors

VARIABLE	FREQUENCY	PERCENTAGES
COMMUNITY-BASED FACTORS		
Distance from the health facility		
Far	83	79
Near	16	15.2
Not Sure	6	5.7
Total	**105**	**100**
Social Stigma		
High	81	77.1
Low	17	16.2
Not Sure	7	6.7
Total	**105**	**100**
Prioritizing Screening (Attitude)		
High	85	81
Low	20	19
Total	**105**	**100**
Community perceptions about sickle cell services offered		
Good	98	93.3
Bad	7	6.7
Total	**105**	**100**

(Source: data from respondents March, 2022)

stroyed and patients present with painful crisis, joint pain, abdominal pain, and complications like anemia", said Key informant D.

Hospital Conditions

The majority (84.8%) of the respondents talked of bad hospital conditions like long waiting hours spent at the hospital, whereas a minority (14.3%) claimed good hospital conditions. Similarly, key informant interviews showed that hospital conditions like time spent at the health facility affect the utilization of sickle cell services.

"Some clients delay at the hospital when they come to utilize the sickle cell services because the queue can be so long", said Key informant A.

6 Discussions, conclusions and recommendations:Discussion of the study findings

Utilization of Sickle Cell Services

There was high utilization of Sickle cell services at 63.46%. Similarly, key informant interviews showed that there is high utilization of sickle cell services. This is because most caregivers of children with SCD know the complications of the disease like pain and anemia which the child would frequently experience if appointment dates are not kept refilling the drugs used to relieve them. Moreover, the services are free. However, the findings differ from that of the PRAMS Working Group, (2010) which found the level of utilization of sickle cell services very low at 13.5% to 15.2%. This could be because they were dealing with women who receive sickle cell services before conception and not caregivers of children with SCD like it was in this research.

Client-based factors contributing to low utilization of sickle cell services

Knowledge of factors contributing to low utilization of sickle cell services

It was found that 100% of the caregivers of children with SCD know about the disease. However, key informant interviews revealed limited knowledge of those caregivers about the disease. The findings from the key informants are similar to that of a study conducted on sickle cell services knowledge among undergraduate women which also showed that lack of knowledge was the greatest barrier to its utilization, (Paulsen, 2017). However, results from respondents are contrary to that found by Paulsen, (2017). This could be because of the difference in the study population, where Paulsen, (2017) used undergraduate women while this study used caregivers of children with SCD, most of whom were revisits who had heard details about SCD in their first visits during health education.

Awareness of clients about factors contributing to low utilization of sickle cell services

The results showed that 95.2% of the respondents are aware while 4.8% are unaware of the sickle cell services offered. This is similar to what the key informants said that majority of the caregivers of children with SCD are aware of the services offered as they hear from their friends and health workers there. These findings are contrary to what Giri and Gautam (2018), and Olowokere *et al.,* (2015) found. As they found that lack of awareness about sickle cell services was a barrier to their utilization. This could be due to the difference in the study area, where SCD is rampant within the community in this study, and those who utilize sickle cell services can be anyone's neighbor, so they can advise in case of any child within their community begins showing signs and symptoms of the disease, which might not be the case with the study area used by Giri and Gautam (2018), and Olowokere *et al.,* (2015).

Vulnerability factors

There is an association between the age of clients (P.V=0.048), their education level (P.V=0.019), and the level of utilization of sickle cell services. However, there is no association between the gender of the clients (P.V=0.907) and the utilization of sickle cell services. This is because education and age may impact the knowledge one has about the disease, hence determining the utilization of services provided for that disease. The findings on gender are similar to those found by Witherspoon & Drotar, (2006) as well as Bitarã es *et al.,* (2008), who did not find any significant association between caregiver's gender with the utilization of sickle cell services. However, the findings on age and education level contradict those of Witherspoon & Drotar, (2006) and Bitarã es *et al.,* (2008), who revealed no significant association between caregivers' age and level of education with the utilization of sickle cell services. This could be due to the difference in study population and study area.

Cost of services

The majority (95.2%) of the respondents said the services are free while the minority (4.8%) said the

Table 4. Shows the results of Hospital-based factors

VARIABLE	FREQUENCY	PERCENTAGES
HOSPITAL- BASED FACTORS		
Adequacy of hospital resources		
High	9	8.5
Low	95	90.5
Total	104	99
Skip	1	1
Total	105	100
Knowledge and skills of health workers		
High	92	87.6
Low	12	11.4
Total	104	99
Skip	1	1
Total	105	100
Hospital Conditions		
Good	15	14.3
Bad	89	84.8
Total	104	99
Skip	1	1
Total	105	100
Health Workers' attitude		
Good	96	91.4
Bad	8	7.6
Total	104	99
Skip	1	1
Total	105	100

(Source: data from respondents March, 2022)

cost is high. It is similar to the key informants who said the services are free of charge. This is because the respondents who talked of the high cost of services were also utilizing the services from clinics and other health facilities which require payment. The findings are contrary to that of Olowokere *et al.,* (2015), which found that people do not seek sickle cell services due to the cost implications. It is because this study was conducted in a Mission health facility that offers mostly fair cost for services since the Implementing partners pay for some of them, yet this may not be the case with that of Olowokere *et al.,* (2015).

Fear of side effects

The results showed that 13.3% of the respondents said the side effects their children experience make them think twice before utilizing the sickle cell services while 73.3% said their children hardly experience any side effects after taking the medications, so they always utilize the services. This is because most of the children with SCD in this study are given only ferrous sulphate plus paracetamol, all of which have negligible side effects. The results are contrary to that of a study that revealed that 62% of patients feared the side effects of SCD medications, thus affecting their utilization of sickle cell services (Brandow *et al.,* 2010). It is also in contrast with another recently completed study in children which found that a quarter of providers reported that more than 20% of their patients refused sickle cell treatment (hydroxyurea) when it was offered to them, for fear of cancer and other side effects (Brandow & Panepinto, 2010). The differences came due to the sickle cell medications being used, wherein those studies; the patients were on hydroxyurea which possesses tremendous side effects, as compared to this study where the majority of the children are on ferrous sulphate and paracetamol, all of which possess minimal side effects.

Community-based factors contributing to low utilization of sickle cell services

Distance from the health facility

The majority (79%) of the respondents said they reside far away from the health unit while 15.2% said their homes are a bit near. This is because Dr. Ambrosoli memorial hospital has large area coverage, and so those who live far away find difficulty reaching the hospitals which affect their utilization of the sickle cell services. This is similar to other studies which indicate that the perceived burden of obtaining medication refills due to long-distance is the primary factor contributing to low utilization of sickle cell services among caregivers of children with SCD (Elliott *et al.,* 2001) (Thornburg *et al.,* 2010); (Witherspoon & Drotar, 2006), and that of Crosby et al., (2012), which found that parents also frequently reported logistical barriers, such as transportation difficulties as barriers to attending clinic appointments. This could be because both studies were dealing with a chronic condition (SCD) that requires a regular visit to the health facility for medication refill and other sickle cell services.

Social Stigma

The majority (77.1%) of the respondents said social stigma is a stumbling block to the utilization of sickle cell services while 16.2% said it is not. This is because most community members perceive SCD as a deadly disease and so they end up back-biting the sicklers and their families. These findings are just like for C. Jenerette *et al.,* (2005), which found that stigma was still pinpointed as one of the factors contributing to low utilization of sickle cell services. In addition, it is also supporting C. M. Jenerette & Brewer, (2010) who found that individuals may face health-related stigma throughout their lives which affects their ability to utilize the sickle cell services and Burnes *et al.,* (2008) who found that mothers to children with SCD reported social stigma and isolation as being coping challenges that affect utilization of sickle cell services. The similarity in findings could be due to related bad community perception of SCD and its prognosis leading to social stigma.

Not prioritizing screening (attitude)

The results showed that 81% of the respondents prioritize appointment dates for utilizing sickle cell services in their daily activities while 19% don't. However, the key informants said the caregivers of children with SCD don't prioritize screening for the disease. The findings of key informants are in support of that of Holtkamp *et al.,* (2017) who found that barriers on a cultural level include: a lack of priority of screening in mainstream healthcare and a lack of demand for screening by the public. It could be because both were talking about the same sickle cell service i.e screening for the disease. However, the results from respondents are contrary to that of Crosby *et al.,* (2012) who showed that parents prioritized work over utilizing sickle cell services. This is because the caregivers in this study know the complications their children would experience if they miss appointment dates which might not be the case with the parents in the study of Crosby *et al.,* (2012).

Community perceptions about sickle cell services offered

It was revealed that 93.3% of the respondents said the community members had good perceptions about the sickle cell services offered at the health facility while 6.7% said bad about it. This is because community members encourage parents of children experiencing signs and symptoms of SCD to go to the health facility, meaning they think positively about those services. The results are in support of that of Jacob *et al.,* (2016), which showed that beliefs by community members about the delivery of services also play a role in utilizing sickle cell services. However, it contrasts with the study which revealed that community perceived maltreatment in the clinic setting and difficulties with provider knowledge or communication, is one of the factors contributing to low utilization of sickle cell services (Valenzuela *et al.,* 2014). This could be because the studies have been conducted in distinct communities that perceive things differently.

Hospital-based factors contributing to low utilization of sickle cell services

Inadequate resources to provide sickle cell services

The majority (90.5%) of the respondents said drug stockouts and inadequacy of screening reagents discourage them from going to the health unit to utilize the sickle cell services while a minority (8.6%) said the opposite. The findings from key informants are similar as they spoke of seasonal drug stockouts which hinders them from providing quality sickle cell services. This is because Dr. Ambrosoli memorial hospital is a Mission facility that receives drugs from donors and purchases through the local collection, and probably the prevalence of SCD is more than they can handle. The findings are similar to a study conducted by Holtkamp *et al.,* (2017) which also revealed limited hospital re-

sources as one of the barriers to the utilization of sickle cell services. The similarity in findings could be because both studies were conducted in areas with a high burden of SCD and the population requiring services could outweigh the available resources.

Limited knowledge and skills of health workers

The results indicated that 87.6% of the respondents said health workers have high knowledge and skills while 11.4% said the contrary. These findings support the key informants who logically defined what SCD meant and described the services they offer. This is because the health workers underwent formal education, so they learned about SCD and also they attend continuous medical education (CME) whose topic can be about SCD, thus enriching their knowledge of the disease. However, the findings are contrary to those found by Newacheck et al., (2000), Seid *et al.,* (2004), and Crosby *et al.,* (2009), all of which revealed limited knowledge and skills of health workers as one of the factors contributing to low utilization of sickle cell services. This could be because the category of the health workers in their studies differs from those in this study. After all, not all health workers bear equal knowledge of SCD.

Hospital conditions

The majority (84.8%) of the respondents said bad hospital conditions like long waiting hours demoralize them from utilizing sickle cell services while a minority (14.3%) disclaimed that. This is similar to the results from the key informant interviews which talked of clients waiting for so long in the queue. This is because of the high burden of SCD yet the clinic day is only Fridays, so the clients can be too many to be handled within a short time. These findings support those from Jacob *et al.,* (2016) who found that approximately one-third of caregivers of children with SCD reported extended wait times and inconvenient clinic hours. This could be because, in both studies, there is too much work to be done by the health workers on the appointment days, yet the clients are too many and cannot be managed in just a blink of an eye.

Health workers' attitude

The results from the respondents showed that 91.4% said health workers have good attitudes while 7.6% said they have bad attitudes when serving them. These findings are contrary to those of Olowokere *et al.,* (2015) and Jacob *et al.,* (2016) all of which revealed the bad attitude of health workers as one of the barriers to the utilization of sickle cell services. This could be due to the way the researcher collected data which accommodates bias, as the respondents may have never felt free to disclose the true characters of the health workers, and it may not be the case with those other studies.

Study limitations and Delimitations

Just like any other studies that possess limitations, this one is no exception. There was insincerity in giving information by participants, which would lead to bias and failure of some health workers to participate in fear of being exposed, which were solved by assuring them that the information was highly confidential and personal identifiers were not used.

In addition, there was non-responsiveness by some participants because of being busy, and that was solved by ensuring appropriate rapport-building with the participants.

7 Conclusions

It was found that there is high utilization of sickle cell services among the caregivers, and some factors affect the utilization positively while others negatively.

For the client-based factors, all of them assessed in the questionnaires increased utilization of sickle cell services, as the clients knew about the disease, were aware of the services being offered for SCD, those services being free in government facilities, and the children experiencing negligible side effects of medications. However, the key informants revealed limited knowledge of the clients in the management of the complications of SCD.

Community-based factors like a far distance from the health facilities that offer sickle cell services and social stigma were found to decrease utilization of sickle cell services while community attitudes towards utilization of sickle cell services and their perceptions towards sickle cell services offered were found to increase the utilization.

Hospital-based factors like the knowledge and skills of health workers, together with their attitudes when offering the services, were found to increase the utilization of sickle cell services. However, hospital conditions like long waiting hours at the hospital and inadequate resources like drugs were found to demoralize the clients from utilizing sickle cell services.

Recommendations:

The health workers should continue providing health education to the caregivers of children with SCD to sustain the high utilization of sickle cell services.

Dr. Ambrosoli memorial hospital should invest in sensitizing the community about SCD through radio talk shows, talking walls, e.t.c just like it is for any other disease.

Policy on the provision of sickle cell services should be amended to empower the lower government health facilities to provide Sickle cell services to reduce the distance from the clients' homes to the health facilities.

Dr. Ambrosoli memorial hospital should also increase the number of sickle cell drugs and reagents ordered from the central drug stores and reinforce their proper management within the health units, to minimize stockouts.

Recommendations for further studies

Further research should be conducted to specifically determine the factors contributing to low utilization of Preconception sickle cell screening, to promote prevention rather than management of SCD.

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List of acronyms and abbreviations

CDC: Centers for Disease Control and Prevention

DHO: District Health Officer

HbA: Adult Haemoglobin

HbS: Sickle Haemoglobin

NA: Not Applicable

OPD: Out-patient Department

Paed: Paediatric

PAG: Pentecostal Assembly of God.

SCC: Sickle cell clinic

SCD: Sickle cell Disease.

SCT: Sickle Cell Trait

SPSS: Software Program for Social Scientists

USCRF: Uganda Sickle Cell Rescue Foundation

WHO: World Health Organization

Operational definitions

Care-givers: Are people taking care of children with SCD.

Children with SCD: Those aged 10 years and below with confirmed laboratory diagnosis of SCD.

Sickle Cell Services: These are services offered by the health care professionals to detect the presence of SCD and guide the individuals with SCD on what to do to minimize the chance of having a child with sickle cell crisis and infections in the future. The services are health education on sickle cell, sickle cell screening, counseling, medical treatment, supportive treatment, etc.

Utilization of Sickle cell services: Means attending health education on sickle cell, being screened for SCD and counseled accordingly, then receiving treatment for children with SCD and enforcing adherence to treatment.

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