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CHALLENGES FACED BY CAREGIVERS OF SICKLE CELL DISEASE PATIENTS ATTENDING WELLSPRINGS HEALTH CENTER III KAMUTUUZA, KALUNGU DISTRICT-UGANDA: A CROSS-SECTIONAL STUDY.

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ABSTRACT.

Background:
Uganda was among the first countries in Africa with a documented large burden of sickle cell disease with over 20,000 babies per year thought to be born with the disease and 25% of them die before their first year of life.

Methods:
A descriptive cross-sectional study that employed both qualitative and quantitative methods was conducted to assess the challenges faced by caregivers of Sickle Cell Disease (SCD) patients attending Wellsprings Health Center III Kamutuuza, Kalungu district. Using a convenient non-probability sampling technique, a total of 50 respondents was obtained. Data was collected using an interviewer-administered questionnaire, analyzed, interpreted, and presented using tables, graphs, and narrations.

Results:
The majority of respondents were females (92%) and 80% were mothers to SCD patients and 52% were aged between 30-39 years. Most of the respondents (52%) were primary-level school drop-outs with 96% belonging to poor (low-income) financial status. The majority (70%) were not knowledgeable about the causes of the disease, 70% reported having stress, 16% were depressed and 60% were not comfortable living with a child with sickle cell disease. The majority (76%) traveled distances of greater than 5 km to access the nearest health facility and 54% reported their minimum waiting time as 30 minutes and above before being attended to by a healthcare worker.

Conclusion:
The findings of this study demonstrated the huge financial and emotional burdens on the caregivers of SCD and suffering exists in various aspects among families of sickle cell patients.

Recommendation:
Counseling and psychosocial support should be routinely provided to children with SCD and their families and there should be the promotion of neonatal screening, genetic counseling, and comprehensive public health education aimed at increasing community awareness of the burden and prevention of the disease. Further research studies to better understand the topic are recommended.

Keywords: *Caretakers, Challenges, Sickle cell disease, Uganda.*
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INTRODUCTION.

Sickle cell disease refers to a group of inherited hemoglobin disorders characterized by a predominance of abnormal sickle hemoglobin in erythrocytes (CDC., 2022). Sickle cell anemia (SCA) results from homozygous inheritance of sickle hemoglobin from both parents and is the most common and severe feature of sickle cell disease (Ndeezi et al., 2016). Sickle cell disease (SCD) is the most common inheritable human hemoglobin disorder seen among people of African, Indian, Mediterranean, Central, and South American descent (Kato et al., 2018; McGann et al., 2018). Patients with SCD frequently experience attacks of pain called "Sickle Cell Crisis," anemia, acute chest syndrome, swelling in the hands and feet, bacterial infections, and even stroke (Kato et al., 2018). These crises occur with varying

frequency, severity, and extent of disability in each individual affected by the disease (Moskowitz et al., 2014).

SCD affects millions of people globally and is particularly prevalent among people in sub-Saharan Africa (Wastnedge E., et al 2018). Over 4.4 million people have sickle cell disease, while over 43 million have Sickle cell trait (SCT). About 300,000 to 400,000 children are born with SCD each year, and over half of these die before the age of five years (Roth GA, et al., 2018). Approximately 23 out of 10,000 people are affected with sickle cell disease (SCD), with the highest prevalence in African countries, 110 out of 10,000 people (Madani et al., 2018). However, SCD is also relatively prevalent in some cultures with high rates of consanguineous and large family size, such as in the Middle East region, including Saudi Arabia, where hemoglobinopathies constitute real public health issues with an overall prevalence rate of 44.1 (42 carriers and 2.1 cases) per 1000 and marked regional variations reaching up to 134.1 per 1000 in the Eastern Region (El-Hazmi et al., 2015).
In Africa, there are 12-15million of the world's total population of those suffering from SCD (Aygun & Odame, 2012) and 50–80% of those die before the age of 5 years (high childhood mortality) majorly because of infectious complications and severe anemia (Aygun & Odame, 2012). The African region has the highest prevalence of SCD with over 75% of the global burden residing in sub-Sahara Africa and an estimated 200,000 babies born with the disease annually (Cooper, Lan, Samir, & Philip, 2017). Due to limited access to early diagnosis and comprehensive SCD care, sub–Saharan Africa accounts for 50% to 90% of SCD-related mortality in children under the age of five years (Grosse et al., 2011).

In East African countries, Tanzania was reported to have the highest prevalence of SCD (12.1%) and a 23% mortality in a prospective cohort study of 506 children of 2 to 12 years in Northwest Tanzania (Hau et al., 2018). In Uganda, a National Surveillance cross-sectional study by Ndeezi et al., (2016) reported that the prevalence of HbSS and HbAS was 0.7% and 13.3% respectively, and in Kenya, a 1.6% and 17.1% prevalence of HbSS and HbAS respectively and 4.5% SCD prevalence at Coast of Kenya (Komba et al., 2018). Generally, the low incidence is documented in highland areas, as in Rwanda and Burundi, owing to the lower malaria endemicity in such areas (Kawuki et al., 2019).

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 13·3% and with the disease was 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).

In a background survey done by the researcher in September 2022 using HIMS forms, it was found that 29%, 32%, and 38% of the general patients attended were sickle cell disease patients for June, July, and August respectively at Kamutuuza Health center Kalungu district. Despite the increasing figures for sickle cell disease per patients registered, there has been no documented literature regarding challenges faced by caregivers of these Sickle Cell Disease patients in Kalungu district. Therefore, this study intended to find out the challenges faced by caregivers of sickle cell disease patients attending Wellsprings H/C III, Kamutuuza Kalungu district Uganda.

METHODOLOGY.

Study design.

This was a descriptive cross-sectional study. It involved both quantitative and qualitative methods. Interviewer-administered questionnaires were used.

Study setting.

The study was conducted at Wellsprings Health Center III from the period of March to May 2023. Wellsprings H/C is located in Bukulula Kamutuuza, Kalungu East, Masaka Uganda. Previously known as The Wellsprings Children's Health Centre. It is surrounded by Lukaya, Kayabwe, Bukakata, Kadugala, Ganda, Ntale, and Mukoko among other areas. Its geographical coordinates are 0°10' 50" South, 31° 50' 56"East. Kalungu district is bordered by Gomba district to the north, Butambala district to the northeast, Mgigi district to the east, Masaka district to the south, and Bukomasimbi district to the west. The district headquarters in Kalungu is 21 km (13 mi) by road, northeast of Masaka City, the largest metropolitan area in the sub-region. Wellsprings Health Center III was the preferred study area because of its uniqueness in the provision of Free sickle cell disease screening, care, and treatment services through support by its donors.

Study population.

The study population included caregivers of patients with SCD attending Wellsprings Health Center III Kamutuuza, Kalungu district.

Sample size determination.

The study included a total of 150 respondents. This sample size was presumed representative enough of the entire study

population. The sample size was determined by the use of Kish and Leslie (1970) formula as stated below: -

$n = \frac{Z^2pq}{d^2}$ Where n=Desired sample size (if the target population is greater than 10,000)

z=Standard normal deviation at 95% confidence interval (i.e.1.96).

p=Proportion of the target (which is 50% or 0.5)

q= 1-p (1-0.5=0.5) is the acceptable degree of error (in this case 0.5)

$$n = \frac{Z^2pq}{d^2} \qquad n = \frac{(1.96)^2 \times 0.5 \times 0.5}{(0.5)^2} \qquad n = 384$$

Since the target population under the study was less than 10.000, the required sample size was then adjusted to a smaller which was estimated as follows;

$nf = \frac{n}{1+(n/N)}$ $nf = \frac{384}{1+(384/150)}$ $n = 150\ respondents$

Sampling procedure.

The respondents were selected using a convenient non-probability sampling technique as whoever was present at the time of data collection was given the chance to participate. The technique was used because it would be difficult to group all the caretakers of SCD patients at once as most patients present for review and treatments on different days. A target number of fifteen respondents was covered per day for a total period of ten days.

Selection of Participants.

The study participants were primary caregivers of patients with SCD who attended Wellsprings H/C III during the study period. A caregiver was defined as a person who cared for someone with SCD and took most of the responsibility and guardianship regarding that patient's treatment during SCD crisis and routine SCD clinic days respectively. Participants were identified and recruited with the help of a nurse and clinician at the outpatient department (OPD) from a list of registered patients with sickle cell disease diagnosis in the OPD register. Using a convenient non-probability sampling technique participants were selected with a ratio of one caregiver to one SCD patient.

Eligibility criteria.

Inclusion criteria.

Any caregiver of an SCD patient who attended Wellsprings Health Center III Kamutuuza during the study period and was voluntarily willing and consented to participate in the study was included in the study.

Exclusion criteria

Caregivers of sickle cell disease patients who did not attend Kamutuuza H/C III for routine care of SCD and all those who were unwilling to participate in the study were excluded.

Bias:

To minimize bias, a convenient nonprobability sampling technique was used, and whoever was present at the time of data collection was given a chance to participate in the study.

Furthermore, before interviewing the respondents, the researchers and the assistants assured respondents that they would be kept anonymous collected information would be confidential, and would never be shared with anyone which encouraged participants to answer questions honestly.

Study variable

Dependent variable: Challenges faced by caregivers of sickle cell disease patients. Independent variables included socio-demographics such as age, sex, religion, tribe, educational level, occupation., Individual/personal challenges and health system-related challenges.

Data Collection Tools and Methods.

Data was collected using an interviewer-administered questionnaire consisting of both open and close-ended questions written in simple and clear language. The questionnaire was developed from the literature reviewed. The questionnaire consisted of four sections, Section A consisted of questions on demographic profile, section B consisted of open and closed-ended questions to determine the socio-economic and Section C consisted of questions to assess individual challenges while Section D consisted of questions to find out the health system related challenges faced by caregivers of Sickle Cell Disease patients attending wellsprings Health Center III Kamutuuza, Kalungu district. The tool was translated into *Luganda* since it is the predominant language used in the study area.

Data Analysis and Presentation.

Data collected was analyzed using Microsoft Excel 2019 Version. The data findings were presented in the form of tables and figures supported by narrations.

Quality controls.

Pretesting of the tool:

The questionnaire was pretested at Wellsprings Health Centre III. This aided the researcher in evaluating the validity and reliability of the questionnaire, and thereafter the tool was updated to eliminate any inconsistencies.

Research assistants.

Four research assistants were selected based on their level of education, communication skills, and knowledge about the topic including the ability to speak fluent Luganda. They were first trained and oriented about the data collection process and then involved in both pre-testing of the questionnaire and final data collection processes.

Field Supervision.

Supervision of research assistants at all times was done by the researchers to ensure all the required data was collected from all the respondents.

Contract duration for data collection.

Respondents were given enough time during data collection so that complete data was collected. This was also done to allow respondents to ask questions or any clarification(s) during the data collection process to enable them to respond accurately to the asked questions.

Ethical consideration.

Ethical approval was sought from Uganda Martyrs University, Research, and Ethics Committee through the Faculty of Health Sciences. Administrative permission was obtained from the administration of Wellsprings Health Center III. Informed consent was obtained from study respondents. All information provided by the respondents is confidential.

RESULTS.

Demographic Characteristics of Respondents.

More than half 78(52%) of respondents were aged between 30-39years followed by those aged between 40-49 years 48(32%), then those above 50 years 15(10%) with the least 9(6%) being 20-29 years.
A greater majority of respondents were females 138(92%) and the minority 12(8%) were males. Most participants 120(80%) were mothers to SCD patients, grandmothers 18(12%) with the least being their fathers 12(8%).
The majority of the respondents 87(58%) reported having two children with sickle cell disease in the family, 54(36%) had one child with SCD, 6(4%) for three children, and 3(2%) for those who had four children with SCD respectively. More than half of the respondents 90(60%) were divorced/separated, 54(36%) were married, with the least 6(4%) being single during the time of study.

Table 1: Demographic characteristics of caregivers of sickle cell disease patients attending Well-Springs Health Center III, Kamutuuza.

Variables	Frequency(n)	Percentage (%)
Age of respondent (years)		
20-29	9	6
30-39	78	52
40-49	48	32
>50	15	10
Sex of the respondent		
Male	12	8
Female	138	92
Family Relationship to the Patient		
Mother	120	80
Father	12	8
Grandmother	18	12
Number of SCD children in the family.		
01	54	36
02	87	58
03	6	04
04	3	02
Marital status		
Single	6	4
Married	154	36
Divorced/separated	90	60

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Socio-economic challenges faced by caregivers of sickle cell disease patients attending Well-Springs Health Center III, Kamutuuza.

The majority of respondents had attained a primary level of education 78(52%), 54(36%) had reached a secondary level, and only 12(8%) were illiterate, with at least 6(4%) having attained tertiary level of education. Regarding occupation status, peasants/farmers doubled as the majority at 93(62%), followed by 30(20%) unemployed, 21(14%) were self-employed with the least respondents 6(4%) being civil servants.

Out of the 30 unemployed respondents, a greater majority 24(80%) reported a reason for no job being about patient care or health problems, and only 6(20%) reported other reasons. Almost all respondents 144(96%) reported being with low monthly incomes with only 6(4%) reporting middle income status.

The majority of the respondents 120(80%) reported being supported financially with medical care and bills by Donor's fund/ project support that was running at the facility, followed by 24(16%) who struggled alone to raise medical bills, and only 6(4%) received support from their spouses. Most respondents 84(56%) were dissatisfied with family support while 66(44%) were satisfied.

Table 2: Socio-economic challenges faced by caregivers of sickle cell disease patients attending Well-Springs Health Center III, Kamutuuza.

Variable	Frequency (n)	Percentage (%)
Respondent's highest level of education		
Primary	78	52
Secondary	54	36
Tertiary	6	4
Illiterate	12	8
Occupation/job status		
Civil servant	6	4
Self-employed	21	14
Peasant/farmer	93	62
Unemployed	30	20
Reason of unemployment		
About patient care or SCD	24	80
Other reasons	6	20
Monthly income status		
Low	144	96
Middle	6	4
Source of support to cater for hospital bills		
Struggle alone	24	16
My spouse	6	4
Donor's fund/ project support	120	80
Level of satisfaction with family support		
Satisfied	66	44
Dissatisfied	84	56

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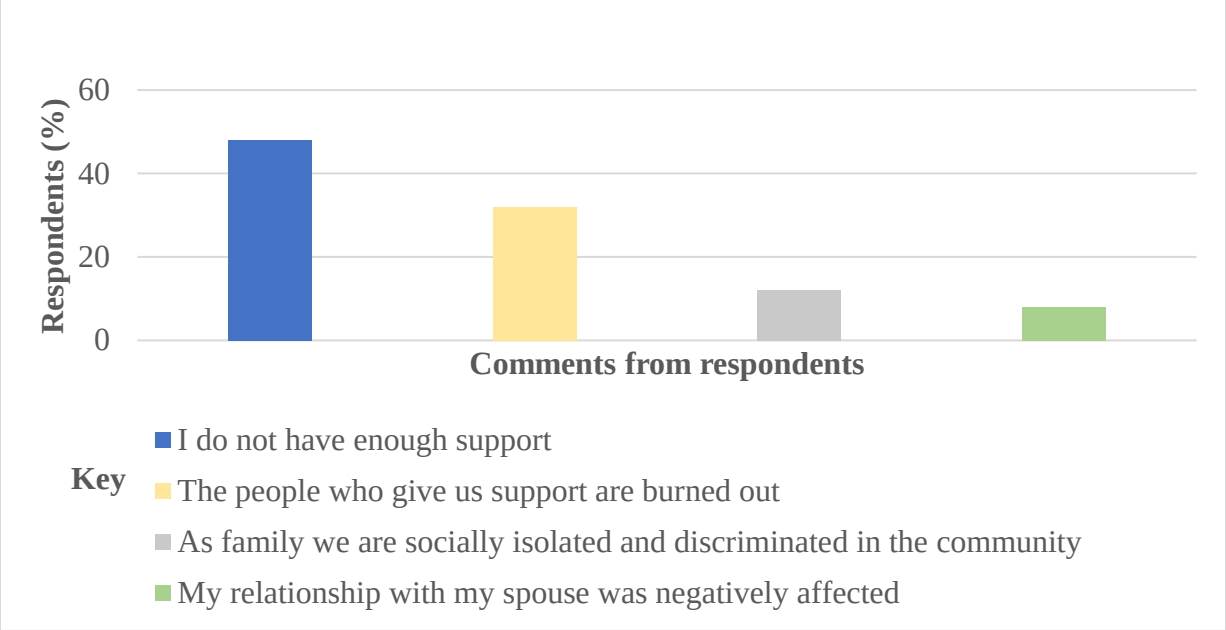
Figure 1: Respondents' comment (s) regarding social and family support from other family members.



Nearly half of the respondents 72(48%) reported not receiving enough support, followed by 48(32%) who reported that people who give them support are burned out, 18(12%) said as a family, they were socially isolated and discriminated in the community, with the least 12(8%) were negatively affected in their relationships with their spouses (as shown in fig 1).

Individual challenges faced by caregivers of sickle cell disease patients.

The majority of the respondents 105(70%) reported not knowing what caused the disease while 30(20%) reported not knowing what triggered the crises with fewer respondents reporting having little knowledge regarding the complications of the disease 9(6%), and 6(4%) the treatment modalities of the disease respectively. Regarding psychological states of respondents, majority 105(70%) reported having stress, followed by 24(16%) depression, with 15(10%) guilty feeling and self-blame and only 6(4%) reported anxiety disorders. More than half of the respondents 84(56%) were frustrated and hurt, 48(32%) regarded the news as being so bad and difficult to feed, and 12(8%) were distressed. The majority 90(60%) were not comfortable living with an SCD child and a high percentage 96(64%) of the respondent's SCD children were not attending school (As shown in Table 3). Out of the 96 participants whose children were not attending school, 59(61%) reported their children always being sick and hospitalized, 15(16%) lacked school fees, 12(13%) their children were discriminated and bullied while at school, and 10(10%) thought there was no need of studying since their child was already sick of sickle cell disease (as shown in figure 2)

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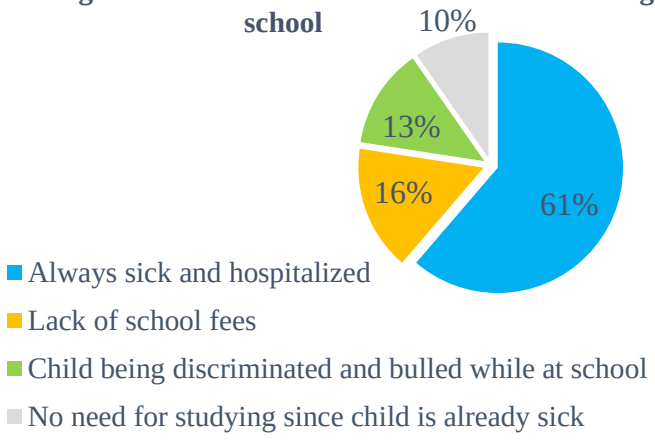
Table 3: Individual challenges faced by caregivers of sickle cell disease patients.

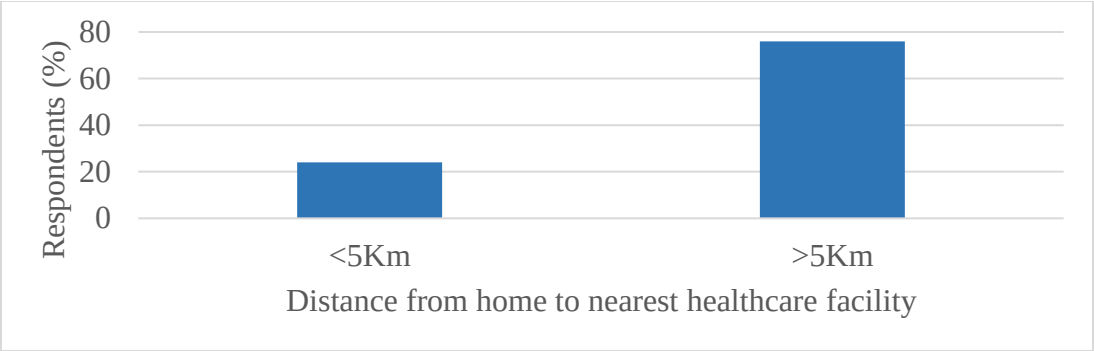
Variable	Frequency (n)	Percentage (%)
Respondents' Knowledge gaps regarding SCD		
I do not know what caused the disease	105	70
I don't know what triggers the crises	30	20
The complications of the disease	9	6
The treatment modalities of the disease	6	4
Psychological experiences faced by respondents		
Stress	105	70
Anxiety disorders	6	4
Depression	24	16
Guilty feelings and self-blame	15	10
Emotional experience and impact of sickle cell diagnosis		
The news was so bad and difficult to feed in	48	32
It was so frustrating and hurting	84	56
Felt very depressed	12	8
Experience and feeling were beyond description	6	4
Whether the respondent is comfortable living with an SCD child		
Yes	60	40
No	90	60
Whether the respondent's SCD child attends school		
Yes	54	36
No	96	64

Fig. 2 showing reasons for children with SCD not attending school



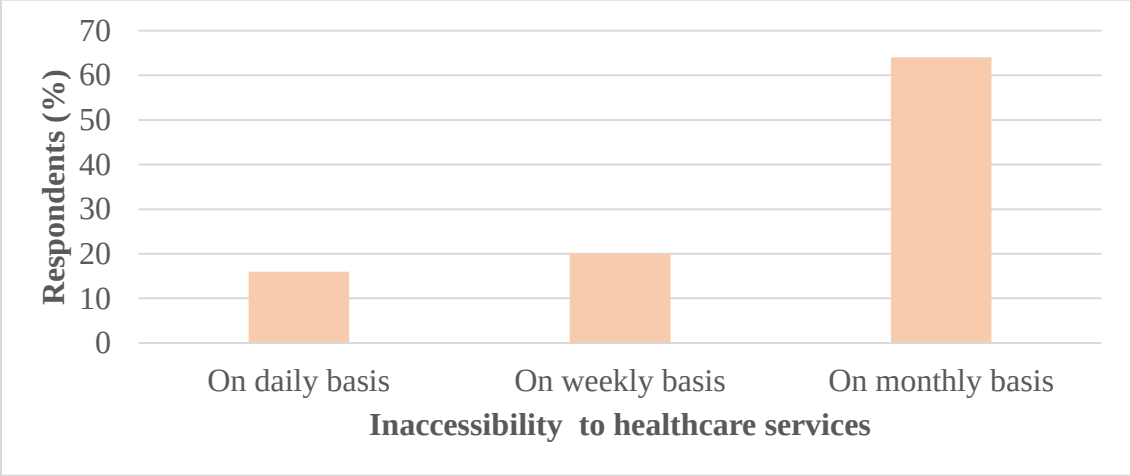
Health system-related challenges faced by caregivers of Sickle Cell Disease patients.

Figure 3: Respondents' distance from home to the nearest healthcare facility.



The majority of respondents 114(76%) traveled distances greater than 5 km to access the nearest healthcare facility with only 36(24%) traveling less than 5 km distance (as shown in Figure 3).

Figure 4: Showing how often respondents lacked transport means to access healthcare services.



The majority of the respondents 96(64%) reported having failed to access the healthcare facility every month due to lack of transport means, with 30(20%) failing every week and 24(16%) daily, as shown in figure 4.

More than half of the respondents 81(54%) reported their minimum waiting time as 30 minutes and above, with 42(28%) between 10-30minutes, and only a few 27(18%) reported their waiting time is less than 10 minutes before being attended to by a doctor or healthcare provider. Most respondents 90(60%) scored well for the quality of healthcare services offered with 6(4%) poor rates. Most majority of respondents 135/150 (90%) reported having special services for sickle cell disease patients at the facility, with 90(60%) reported being given priority at the emergency care when a child is in crisis, 45(30%) reported being attended to in sickle cell clinic and reduces on their waiting time, and 15(10%) reported their patients being initiated and monitored on hydroxyurea at no costs (as shown in Table 4).

Table 4: showing the quality of care Health system-related challenges faced by caregivers of SCD patients.

Variable	Frequency (n)	Percentage (%)
Minimum waiting time at the healthcare facility		
Less than 10 minutes	27	18
Between 10 to 30 minutes	42	28
30 minutes and above	81	54
Quality of healthcare services offered		
Good	90	60
Poor	60	40
Whether there are special services offered for SCD patients at the facility		
Yes	135	90
I do not know.	15	10
Special Services available		
Being given priority at the emergency department when a child is in an SCD crisis	90	60
Being attended to in the SCD Clinic reduces waiting time	45	30
SCD patients are being initiated and monitored on hydroxyurea free of charge.	15	10

DISCUSSION.

Socio-economic challenges faced by caregivers of Sickle Cell Disease patients.

Most of the respondents (52%) were primary-level drop-outs. However, the government of Uganda offers free primary and secondary education in government-aided schools. It also provides scholarships and loan scheme program that benefits some students for tertiary level education. These findings conquer with studies by Franklin et al, (2018) and Shayesteh et al. (2020) where a large population of people living in developing countries had a low level of education which limited their understanding of many diseases and ended up connecting hereditary diseases with curses and witchcraft. Due to poverty, some people in developing countries either have no formal education or only have primary education (Franklin et al, 2018). This necessitates the need for awareness campaigns to educate the community regarding hereditary diseases such as SCD.

The financial burden was the dominant variable among caregivers. Many had financial problems, with the majority (96%) indicating their poor (low income) financial status, which probably worsened when the child experienced a sickle cell crisis and was hospitalized. Individuals with SCD have to deal with frequent hospital visits, hospitalization, and comorbidities such as bacterial infections, malaria, and anemia (Saif et al 2022). Furthermore, having a child with SCD reduced the productivity of most of the parents as they reported having less time to engage in different income-generating activities such as farming and entrepreneurship that would help in health expenditures for the child and housekeeping expenses (Shayesteh et al., 2020). The less involvement in work has resulted in a substantial reduction of productivity Caregivers revealed that they are facing economic burdens resulting from healthcare demands for their children with SCD (Kilonzi et al. 2022). Caregivers' low-income status wound be linked to increased expenses during admissions in cases of sickle cell crisis since they must buy food, while others buy medications that are not usually provided by the admitting hospital for free of charge. Furthermore, some caregivers had to be absent several times or even leave their jobs to take care of their children, which impacted their earnings. This was reflected by 20% of respondents who reported being unemployed, with 80% of them linking unemployment to patient care and or health problems associated with sickle cell disease. These findings were in line with Madani et al, (2018) that found that financial stress was described as a significant factor for caregivers' difficulty coping with their afflicted children; and the psychosocial impact of the financial burden was more remarkable during SCD crises.

Regarding support from family and relatives, most respondents (56%) were dissatisfied with family social support. This was possibly demonstrated by the extent of psychological and financial support received by caregivers

mostly coming from their natural social environment; especially from partners, other family members, friends, and neighbors. In the same regard, nearly half of the respondents 48% reported not receiving enough support, 32% reported that people who give them support are burned out, 12% said as a family, they were socially isolated and discriminated against in the community and 8% reported negatively affected in their relationships with their spouses. On the other hand, most of the tasks and responsibilities related to caregiving were home-centered and undertaken by the exclusive caregivers (Jacob et al., 2022). The activities included helping patients take medications, assisting them during recurrent disease complications and intermittent crises, carrying them to the clinics and hospitals for recurrent blood transfusions or periodic visits, as well as communicating with hospitals and schools. These findings were in line with those by Brennan-Cook (2019) where more than half of the interviewees declared a lack of time to take care of themselves with relatives exhibiting low participation rates in various daily activities concerning the sickle cell disease child.

Individual challenges faced by caregivers of Sickle Cell Disease patients.

This study revealed that the majority of the respondents (70%) reported not knowing what exactly caused the disease and 20% reported not knowing what triggered the crises. These findings indicated that there were knowledge gaps amongst caregivers of SCD patients regarding the causes of the disease and its precipitating factors that evoke the onset of a crisis. This was linked to individual education levels as the majority of respondents (52%) were primary-level dropouts, and or lack of health education from the healthcare workers during the time of diagnosis and routine visits. These findings were in agreement with those by Wasomwe M.M., and Ngoma.C., (2015) which revealed that the knowledge level of SCD among the majority of respondents (83%) was low. The low level of knowledge was attributed to the fact that the majority of the respondents (71%) had a low educational level and probably the majority of respondents had not been counseled on SCD and had not received any educational materials regarding SCD.

Regarding the psychological states of respondents, the majority (70%) reported having stress, 16% depression, 10% guilty feelings and self-blame, and 4% reported anxiety disorders. Sickle cell disease being a chronic illness, it affects individuals of the whole family and more especially the immediate caregivers in all aspects of life including social, financial, spiritual, and emotional consistently and even worse during sickle cell crisis (Amour & Jumanne., 2021). This therefore probably increases the risks of caregivers getting chronic stress and psychological well-being. From the time of diagnosis, 56% of respondents were frustrated and hurt, 32% regarded the news as being so bad and difficult to feed, 8% were distressed and the majority of the respondents (60%) were not comfortable living with an SCD child. All these contributed to the respondent's psychological unwell being. These findings were in line with those by Ali, and Razeq (2017) on the Lived Experience of Parents of Children with Sickle Cell Disease where parents reported the severe emotional impact of learning about the SCD diagnosis in their children.

The current study findings were in line with those by Wasomwe and Ngoma (2015) in a study to assess problems encountered by immediate family members in caring for children affected with Sickle Cell Disease in Lusaka, Zambia where the majority of respondents (77%) experienced depression, guilt feelings, anxiety, and blue moods due to living with a child affected with SCD. There was a significant association between the number of times the child had been hospitalized and depression in the parent. The study also revealed an association between feelings of guilt and levels of knowledge of SCD by the respondents and this was in line with study findings by Madani et al, (2018) which also showed that emotions, sleep quality, and sexual life were the most affected dimensions in caregivers of children with SCD.

The majority (64%) of the respondent's SCD children were not attending school and among the reasons suggested, the majority (61%) reported that their children were always sick and hospitalized, 16% lacked school fees, 13% of their children were discriminated and bullied while at school, and 10% thought there was no need of studying since their children were already sick of sickle cell disease. These findings were matched with those by Hau et al, (2018) among the children with sickle cell anemia (SCA), 72.3% of them could not go to school, 68.9% stayed in the hospital at least 1 – 5 times a year and 77.2% needed regular blood transfusion**.**

Health system-related challenges faced by caregivers of Sickle Cell Disease patients.

The SCD sufferers, as well as their caregivers, are faced with several challenges such as daily use of routine drugs, recurrent or frequent illnesses, the need for blood transfusion, regular clinic attendance, and hospitalization (Jacob et al., 2022). In the present study, more than half of the respondents (54%) reported their minimum waiting time as 30 minutes and above, before being attended to by a doctor or healthcare provider. This was in line with findings by Brennan-Cook et al, (2019) where dissatisfaction with hospital facilities was identified as a major challenge and most caregivers discussed experiencing delays in the emergency room. They waited several hours before receiving treatment. In addition, they had to wait several hours and sometimes days in the emergency room until the patients were shifted to the appropriate wards. Supportive

findings by Kilonzi et al, (2022) also noted that visits to emergency departments were not smooth as long waiting hours in the emergency room were among the major problems faced by most caregivers.

In addition, long distances traveled to access healthcare facilities was another major challenge identified as the majority of respondents (76%) traveled distances of greater than 5 km to access the nearest healthcare This could be linked to several factors which may include inadequate healthcare facilities, inadequate staffing of healthcare workers, late coming of healthcare workers, and possibly bad attitude of some health workers. In a study by Freiermuth et al., (2014) lack of adherence to treatment guidelines by the caregivers of SCD was closely associated with negative provider (health worker) attitudes.

In this study, a greater majority of respondents (90%) reported having special services for sickle cell disease patients at the facility, with 60% reported being given priority at the emergency care when a child is in crisis, 30% reported being attended to in sickle cell clinic and reduces on their waiting time, and 10% reported their patients being initiated and monitored on hydroxyurea at no costs.

CONCLUSION.

From the study findings on the challenges faced by caregivers of Sickle Cell Disease patients attending Wellsprings Health Center III Kamutuuza Kalungu district, the following conclusions have been made; Majority of the respondents (caregivers) were females, most of which belonged to 30-39 years age group and a bigger percentage were mothers to sickle cell patients.
Most caregivers were primary-level school dropouts, unemployed with low monthly incomes, and had less knowledge regarding the causes of the disease, trigger factors for a sickle cell crisis, and treatment options for the disease. Depression and chronic stress were dominant psychological disturbances reported by respondents while long waiting times, lack of transport, and traveling long distances to access the nearest health facility were the major health institutional challenges identified by the majority of respondents.

RECOMMENDATIONS.

1. Counseling and psychosocial support should be routinely provided to children with SCD and their families. Forming patient/parent support groups and linking families to civil societies and NGOs with an interest in SCD is another way of supporting these.
2. The Ministry of Health and the global stakeholders should prioritize the promotion of neonatal screening, genetic counseling, and comprehensive public health education aimed at increasing community awareness of the burden and prevention of the disease.
3. Pediatricians and healthcare providers should be aware of the huge burdens on caregivers and orient them towards appropriate solutions, to help them meet their needs and improve their quality of living and that of their diseased children.
4. Further research studies are recommended to better understand the challenges experienced by caregivers of sickle cell disease children and how they can be overcome.

STUDY LIMITATIONS.

This study was cross-sectional and was carried out in only one rural setting and thus findings may be difficult to generalize to a much larger population. More studies are, therefore, called in this field of study.

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