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Facilitators and Barriers to Self-care Management of Sickle-Cell Disease among Caretakers of Children with Sickle-Cell Attending a Regional Referral Hospital, Eastern Uganda: A parallel Convergent design

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Abstract

Background: Sickle cell disease is a hereditary disease caused by a derangement of the β -globin gene and is characterized by sickling of the red blood cell. Globally the effect of sickle cell was acknowledged to have a great public effect with the great effect being in Africa where mortality rate in children below five years was above 50%. Home based practices are integral to prevention of sickle cell crisis. The aim of this study was to explore the facilitators and barriers to adherence to home-based practices towards the management of sickle-cell disease among caretakers of children with sickle-cell attending Mbale regional referral Hospital.

Methods and materials: A Parallel convergent design was utilized. For the quantitative arm a simple random sampling was employed, questionnaires were used to collect the data by a direct interview method; data collected was entered into Stata version 17 for statistical analysis. For the qualitative arm a purposive sampling was used, in-depth interview guide was used to guide the in depth interview. Data collected was analyzed using Braun & Clarke's approach.

Results: Most participants were mothers (66.5%), married (87%), and self-employed (88%) with the majority being the Bagwere tribe (56%). The home based practices were divided in the themes of use of herbal medicine, following medical advice and pain crisis management. Barriers to home based care practices were health system gaps, financial constraints, transportation difficulties and falling sick burden. The facilitators to home based care were of financial and emotional support, health worker support, hospital support, and adherence to medical advice.

Conclusion: This study demonstrates that adherence to home-based care practices for the management of sickle cell disease among caregivers remains sub-optimal, exposing affected

children to preventable complications and frequent illness episodes. Caregivers' ability to effectively manage SCD at home is strongly influenced by social, financial, and health system factors, including limited knowledge about the disease, financial constraints, transportation challenges, and gaps in health service support. At the same time, the presence of supportive health workers, access to hospital services, social and emotional support, and adherence to medical advice were identified as key facilitators of effective home-based care. These findings highlight the need for comprehensive, family-centred interventions that strengthen caregiver education, improve financial and social support mechanisms, and enhance continuous engagement between caregivers and health workers.

Clinical trial number: Not applicable

Key words: Factors ; Adherence ; Self-care Management; Sickle-Cell Disease; Caretakers; Children; Regional Referral Hospital; Eastern; Uganda

Background

Self-care management of sickle cell disease comprises of all actions recommended by the healthcare practitioner, but carried out at home in the absence of the health care practitioner and required to improve psychosocial conditions, prevent health complications, and maintain health among individuals living with sickle cell [1]. Sickle cell disease is a hereditary disease caused by a derangement of the β -globin gene and is characterized by sickling of the red blood cells. All around the globe, sub-Saharan African countries bear the highest burden of sickle cell disease [2, 3]. The United States Centre for disease control and prevention CDC [4] described Sickle cell trait (SCT) as a heterozygous state following the inheritance of one sickle cell “S” allele from one parent and one normal hemoglobin (Hb) “A” allele from the other parent. An individual with SCT or heterozygote (HbAS) typically does not show symptoms of sickle cell disease (SCD) or mutated homozygote (HbSS), although they may pass the trait on to their offspring [5].

Available evidence demonstrate that Sickle cell disease (SCD) is a hereditary disorder commonly found in people of African descent, mainly in tropical areas of sub Saharan Africa [6]. The inherited blood disorder affects the structural shape of the red blood cells and marked by abnormal hemoglobin-S (HbS) as opposed to the normal hemoglobin (HbA) [7, 8]. Approximately 20-25 million people are living with SCD with the highest number coming from Sub-Saharan Africa [9, 10]. Around 100,000 individuals suffer from the SCD with most (800/100,000) in Africa and black people being known to carry the disease [11, 12] The pathogenesis of Sickle cell crisis was such that the sickle cell blocks the flow of blood this occurs because the sickle shape of the blood makes them stuck in the blood vessels, this slows blood supply and as such pain occurs [13]. In severe cases more especially among children, interruption of blood flow can result into death of the tissue. The most affected parts being the legs, the arms and the chest [14, 15].

The global effect of sickle cell disease has been acknowledged to have a serious public health impact with the greatest impact being felt disproportionately in Africa where mortality rate among children under 5 years has been reported to be as high as 50% and in other countries in the continent hitting a record high mortality rate of 80% [3]. Available evidence show that world over, about 7.74 million had sickle cell disease [16].

Home-based care practice was integral to prevention of the occurrence of sickle cell crisis. It included intentional performance of specific tasks, skills, activities, and behaviors learnt with a goal of managing the medical, psychosocial, and life impact of Sickle Cell Crisis [17, 18]. Patient's behavior was core to self-care management of SCD [19]. Clinicians should pass on care skills to treatment supporters through services like social support and health education. Care takers empowered through health education become knowledgeable with the resultant improvement in health outcome. Health care workers can also help improve self-care by proper utilization of health resources, being more available to patients and their care takers among others [20, 21].

In study of home-based care practices in the management for sickle cell disease among patients' caregivers, Druye, Nelson [22] described that some of the home-based care practices by care givers included keeping warm by putting on warm clothes, taking plenty of water in order to keep hydrated in addition to eating the right foods. Patient -monitoring skills include checking for anemia, color of urine and spleen enlargement. It also involves checking for warning signs and their management [23]. The warning signs that need to be explained to care takers include fever, enlarged spleen, fever, pain in the legs, arms and the chest. Management of fever and pain are the most common patient-care skills among care takers however accessing the pain killers was at times limited by inadequate resources at house hold level was a challenge [24].

Globally, SCD contributed a considerable burden of disease that was not appropriately addressed [2]. Approximately 312,000 children worldwide were born with SCD annually [25]. Sub-Saharan Africa has the highest burden, where 75% of the world sickle cell disease is found [3].

A big burden of sickle cell trait and disease exist in Uganda with an estimation of 15,000 babies being born with sickle cell disease every year [26]. Uganda occupies the 5th position in the ranking of sickle cell burden across Africa. 13.3% of children are carriers and 5,000–20,000 babies are born with SCD every year, with 80% the children dying before making 5 years of age [25]. The occurrence of Sickle cell trait varied all over Uganda, where Central Uganda took 12.8%–19.8% of the cases, 13.6% in Kampala District and 26.3% in eastern Uganda [26]. Although there had been deliberate effort by MOH to screen all of the new born and infants below 2 years of age for sickle cell disease or trait in districts with high incidences of SCD, there a number of challenges encountered ranging from poor knowledge among parents as to whether SCD is an inherited condition to inadequate knowledge and understanding of SCD being a medical condition. This coupled with lack of awareness on the transmission of sickle cell disease and poor adherence to home-based care practices has greatly affected the management of SCD [27]. Social barriers existed for improving SCD care and outcomes, including home-based care practices, an overall lack of awareness about SCD, understanding of SCD as a medical condition, and its inheritance [28]. Home-based care practices in regards to the management of sickle disease in Uganda were found to be poor. However, the factors associated with this poor home-based care practices remains unknown. It is therefore against this background that this study aimed to explore the factors influencing adherence to home-based care practices towards the management of SCD among caretakers of children with sickle-cell disease attending Mbale regional referral Hospital

Evidence showed that sickle-cell crisis remained a major public health challenge among children with sickle-cell with a world prevalence 0-18.2% vaso-occlusive crisis per year [29]. The major factor associated with the development of sickle-cell crisis among children living with sickle-cell disease was poor home-based care practices [30]. Sickle cell patients continued to experience crises despite the existence of home-based care practices toward prevention and management of sickle cell disease[31, 32]. This complicated the management of SCD leading to complications and early death of the patients [33].

Adherence to home-based care practices in regards to the prevention of sickle-cell crisis was associated with reduced morbidity and mortality among patients with sickle-cell disease [34].

Findings from Uganda showed a high prevalence of sickle cell disease estimated to be 9.7% among children [35]. Among the children with sickle cell disease in Uganda, sickle cell crisis remained the most common cause of need for hospitalization with an incidence of 6.4 sick visits per year [36].

A study conducted at Mbale Hospital demonstrate that despite caretakers' high awareness in regards to sickle-cell disease, good knowledge and positive attitude towards the management of sickle-cell disease, their practices towards the management of sickle cell disease remains poor with only 43% giving their children pain killers and only 38% ensuring adequate hydration to prevent sickle-cell crisis [37]. These poor practices in regards to management of sickle-cell disease were responsible for the high morbidity evidenced by high burden of sickle cell crisis in the hospital which was found to be 32% in the month of April 2024 (HMIS 105).

What remained unclear were the factors that could explain the poor practices in regards to management of sickle cell among the care takers of sickle-cell children at this Hospital. As a

consequence, it was important to understand the factors that lead to the poor adherence to self-care practice in the management of sickle-cell among the caretakers. Therefore this study explored the factors which led to poor home-based practices among caretakers of children with sickle-cell attending Mbale regional referral Hospital. The findings of this study will be used to inform targeted interventions towards improving caregivers' adherence to home-based practices in prevention sickle cell crisis. The aim of this was to explore the facilitators and barriers to adherence to home-based care practices towards the management of sickle-cell disease among caretakers of children with sickle-cell disease attending Mbale regional referral Hospital.

Methods and materials

Study design

A parallel convergent design was utilized. This design was a mixed method where the quantitative approach and qualitative approach are done concurrently. The findings are then merged at discussion [38].

Study area

This study was held at the Sickle Clinic in Mbale Regional Referral Hospital located in the center of Mbale City, 250km east of Kampala, a capital city for Uganda. MRRH works as a regional referral Hospital for other nearby districts like Busia, Manafwa, Bududa, Budaka, Kibuku, Kapchworu, Bukwa, Butaleja, Palisa, Sironko, Tororo, and Mbale district. MRRH serves a population of over 4.6 million people who come from the above mentioned districts. It was started in 1924 as a health center and now has grown to 450 bed capacity. The Hospital offers in patient services, outpatient services, diagnostic services, private patient services, and emergency services

169 and the Clinic handled both clients who came for review from home and those being managed on
170 the wards.

171 **Study population**

172 The study focused on care givers of children with sickle cell disease.

173 **Eligibility criteria**

174 **Inclusion**

175 Caregivers aged 18+ years, caring for children with SCD, and of sound mind.

176 **Exclusion criteria**

177 Caregivers of critically ill children were excluded.

178 **Sample size determination for quantitative arm of the study**

179 The sample size was determined using Leslie Kish formula [39] below,

180
$$N = \frac{Z^2 PQ}{d^2}$$

181
$$d^2$$

182 n= the desired sample size. Z= the value that corresponds to the 95% confidence interval which is
183 1.96, P= the probability of an event (prevalence of 20%) this was published in new vision of 02nd
184 November 2022 (Dr. Musinguzi Francis), q= 1-p = 0.5, d= the degree of precision of error to be
185 committed which will be 5% (0.05), $n = (1.96^2 \times 0.20 \times 0.5) / 0.05^2$, $n = 150.5 = 151$. Factoring in a
186 10% non-response rate, the minimum sample size was adjusted to 165 participants. To ensure
187 robustness, the study recruited a total of 200 participants.

Sample size determination for qualitative arm of the study

For qualitative arm of the study, data saturation was employed to determine the sample size. This saturation was determined when no new information emerged from the participants. In this study, full saturation was reached at 15 participants.

Sampling procedure

For the quantitative arm, respondents were selected using a simple random sampling technique. Eligible participants were given random numbers using Microsoft excel software in which a number of care givers available during the day of data collection was got and random numbers generated. A target number of fifteen respondents was covered per day for a total of 11 days. For the qualitative component, participants were selected purposively where only participants that were deemed to be rich in information and relevant data were recruited.

Study variables

Dependent variable

Adherence to home-based care practices

Independent variables

Age, sex, educational level, income level, distance to the facility, cultural belief among others.

Data collection tools

The data collection tools for this study were questionnaires and an in-depth interview guide.

Questionnaire

A standard questionnaire was adapted from a study of adherence to self-care management of sickle cell disease among care givers [1] which was then administered to selected care-givers attending

sickle cell clinic who met the inclusion criteria. The questionnaire was used to collect quantitative data and it comprised of closed ended questions and statements with predetermined responses in a three point likert scale. This three-point Likert scale was defined as: 1 = Never a problem, 2 = Sometimes a problem, 3 = Always a problem

Interview guide

An interview guide which was developed by the researchers after a thorough literature. The interview guide contained open ended questions with follow-up probes which guided the data collection process.

Data collection procedure for quantitative

After approval from the department of nursing and Research and Ethics at Busitema University Faculty of Health Sciences, administrative clearance was obtained from the Director Mbale Regional Referral Hospital. An informed consent was obtained from each of the research participants. Quantitative data was collected using semi-structured questionnaires. In this method the questions and options were read by the research person to the participants, the responses by the participants were entered.

Qualitative data collection procedure

In depth interviews and were used to collect data. This comprised of open ended probing questions which the study participants used to express their views in regards to adherence to home-based care practices. Data was collected using a voice recorder after seeking participants' consent to record their voices. The study was conducted in a private room within the hospital to allow privacy. The interview took 30minutes to 1hour and the participants were free to ask any question for any

clarification. Ink pens were used to note the nonverbal cues expressed by the participants. This provided important text to the interpretation of the audio-taped data during data analysis.

Data management for quantitative data

After data collection, it was entered into excel in which it was cleaned coded, then it was entered into STATA version 17 for statistical analysis. It was then kept under pass codes and only accessed by authorized personals.

Data management for qualitative data

Data was stored under safe custody, preserved, and shared with only among the research team for the research purpose. The information was stored under double locked box and the soft copy stored in the flash disk only accessible by the researchers.

Quantitative data analysis

The decision mean (also called the cut-off mean or threshold mean) was used to interpret how frequent or severe a problem is perceived by respondents. Calculation of Decision Mean was done as follows: $\text{Decision Mean} = (\text{Lowest value} + \text{Highest value}) / 2 = (1 + 3) / 2 = 2.0$. The interpretation of the likert scale was based on the score range as follows: 1.00 – 1.99 meant the problem is rare or negligible; 2.00 meant that the problem is occasional/moderate; 2.01 – 3.00 meant that the problem is frequent or severe. The results for adherence to home-based care practices for self-management of sickle-cell was analyzed by determining their frequencies and percentages. To rank adherence towards self-care management of sickle cell disease as poor and good this study employed guidance by Patel, Lindsey [40] who stated that patients who filled their medications 75% of the required time are considered completely adherent. The total attainable percentage adherence in this study was 100% (10/10). Therefore, participants who score

less than 75% were considered to have low or poor adherence and those above 75% were considered to have good adherence.

Data analysis for qualitative

Data analysis employed thematic analysis by Braun & Clarke (2006) that involved the six-phase to generate themes. It entailed: **Familiarized with the data**; this was done by reading and re-reading the translated transcript to gain familiarity with the entire body of the data corpus and notes jotted down for early impressions. **Generated initial codes**; data was organized in to meaningful and systematic way by coding to reduce lots of data into meaningful small chunks using the pen and highlighter on the hard copy of the translated transcript. **Searched for themes**; significant or interesting information about the data and/or research question was captured by examining the codes and fit them together into a theme. **Reviewed themes**; there was review, modification and development of preliminary themes that had been identified to make sense by gathering together all the data relevant to each theme. **Defined the themes**; final refinement of the themes was done with the aim of identifying the ‘essence’ of what each theme was about and how the subthemes interacted and related with the main theme. Finally writing up the final narrative.

Quality control for quantitative

Validity: Validity is the degree to which the scores accurately reflected the variables. To determine whether the questions were capable of gathering the desired data, validity test was performed. The research tools were pretested to allow necessary adjustments in the questionnaires. Irrelevant and vague questions were removed; some questions were rephrased so that they collect the intended data. To determine the validity of the study instrument, a Content Validity Index (CVI) was generated from two expert reviews. The content validity index for the tool was 0.8.

Reliability: The reliability of an assessment tool refers to its ability to consistently produce stable results. For the tool to be considered reliable, it should yield similar outcomes when used repeatedly to measure a specific characteristic among the same respondents. To ensure reliability, specifically, questionnaires were administered to 10 randomly selected caregivers of sickle cell patients. The Cronbach's alpha which the measure of consistency employed was. The Cronbach's alpha was 0.8182 for the items that assessed the adherence to self-care management of sickle cell disease. Additionally, the researcher recruited and trained three experienced research assistants on the study's relevant aspects.

Rigors for qualitative

The study rigor was achieved by maintaining trustworthiness; making the study suitable, reliable and acceptable hence believability of the study. This was based on the four criteria of evaluating trustworthiness of data and interpretation as described by Lincon and Guba, (1985) which included; credibility, confirmability, dependability, and transferability. **Credibility is the truth & confidence in the truth of findings** [41, 42]. This was ensured through adopting well established research methods, persistent observation/familiarity with phenomenon, prolonged engagement with data in this study, purposive sampling of the caretakers, translating the tool into local language to enable the caretakers understand and express themselves freely, transcribed the recorded data verbatim in local language and translated it in to English and back translated it into local language. The tool was pretested to ensure there was clarity, no ambiguity when answering the research question. **Confirmability** is the level of confidence that the research study's findings are based on the participants' narratives and words rather than potential researcher biases [43, 44]. Confirmability was ensured through audit trail that included raw data, such as audio recorded materials, written field notes, member checks and records. By tying together, the data analytic

process and results, the reader was in position to confirm the adequacy of the findings, and verified the study when presented with the same data. The researcher applied reflectivity throughout the study to guard against personal beliefs, assumptions, motivation or biases about him-self, the participants, and the study setting [45]. **Dependability:** Dependability is consistency and reliability of the research findings and the degree to which research procedures are documented, allowing someone outside the research to follow, audit, and critique the research process. This was achieved by providing a detailed description of the research methods [46, 47]. **Transferability:** The extent to which the study finding can be applied to other setting [48, 49]. Transferability was ensured through thick description of the study, which involved providing adequate details on the site, participants and methods that will be used to collect data during the study. This gave a reader to decide whether the study can be transferred to their study [50].

Results

Quantitative results

Social demographic characteristics of the participants

Most of the participants were mothers (66.5%), married (87%), and self-employed (88%). The dominant tribe was the Bagwere (56%), and most were Christians (63.5%). Most had a monthly income of 50,000–74,999 Ugandan Shillings (36.5%), and most of the sickle cell children were 6–10 years old (62%). The average family number was 4.97 members, with each family having average of 2.47 adults and each child at least fell sick on average of 1.23 every month. The results are summarized in Table 1.

Adherence to self-care management of sickle cell disease

The overall percentage mean adherence to the self-care management of sickle was 67.35%. Evaluation of each element of self-care management resource showed that adherence to sleeping under insecticide treated mosquito net was the most observed in this study which was found at 91.67%. On the other hand, adherence to penicillin was the least observed in this study which was found at 59%. The mean adherence score and standard deviation of each self-care management regimen are summarize in Table 2. Mean adherence rates were measured as the mean value divided by the maximum possible value for each item then multiplied by 100. Overall or total adherence rates in this study ranged from 30% to 90% with a mean adherence rate of 67.5%. The overall adherence rates had a median 70%, and a 25 and 75 percentile of 60% and 80% respectively. Only 44.50% of the participants had adherence rates over 75%.

Knowledge towards sickle cell disease

The mean knowledge score of the participants is 6.9, standard deviation is 1.7272. The percentage mean score is 63.273. The minimum score was 2 and the maximum score was 9. The denominator score is 11. Of the 200, about 95.5% did not know type of sickle their children had. Most participants (96%) recognized joint pain as a symptom of sickle cell disease, 77% identified swollen limbs, and 94.5% disagreed with anemia to be symptom of sickle cell disease. About 48% agreed that malaria causes symptoms in sickle cell while 52% disagreed, 58% agreed that anemia causes sickle cell symptoms, 42% disagreed, and 75.5% agreed that coldness causes sickle cell disease symptoms. About 88% agreed that medication prevents pain crises, 85% agreed that warmth prevents pain crisis, and 62% agreed that hydration prevented pain crisis. The results are summarized in Table 3.

Correlation between Knowledge towards sickle cell disease and adherence to self-care management of sickle cell disease

Shapiro-wilk's test for normality was done for score on adherence and knowledge towards self-care management of sickle-cell disease. The test rejected the null hypothesis that the data was not normally distributed with both having ($p < 0.00001$). Since the two scores were not normally distributed a spearman's test for correlation was done between knowledge towards sickle cell disease and adherence to self-care management. The spearman's correlation test demonstrated that there was no correlation between knowledge towards sickle cell disease and adherence to self-care management of sickle cell disease ($r_s = 0.0867$, $p = 0.222$).

Barriers to adherence to self-care management of sickle-cell disease

The results indicated that most (52%) of the participants reported forgetting to be never a problem, 51% reported difficulty getting medication sometimes a problem, 47.5% reported time constraint sometimes a problem, 48% reported Cost of medication being sometimes a problem, and 39% reported taste aversion sometimes a problem. About 52.5% reported obtaining Fansidar not difficulty at all, 51% reported not at all difficulty to get folic acid, 48.5% reported not at all difficulty to get Penicillin, 50% reported not at all difficulty to obtain mosquito net. About 42.5% reported portable water not at all difficulty to obtain. Less than half (44.5%) reported somewhat difficulty to administer fansidar, 48% reported not all difficulty to administer penicillin, 44% reported not at all difficulty to administer folic acid, 47% reported not at all difficulty to administer proguanil, and 47% reported not difficulty at all to make child sleep under the net. 58.5% reported not at all difficulty to remember to administer fansidar, 57% reported not all difficulty to remember to administer penicillin, 60.5% reported not all difficulty to remember to administer folic acid,

63.5% reported not at all difficulty to administer proguanil, 64% reported not at all difficulty to remember make the child sleep under the net, and also 64% reported not at all difficulty to remember to provide child with water. The results are summarized in Table 4.

Qualitative results

Caregivers' Knowledge and practices of home based care

We first explored the first explore the caregivers' knowledge and home based care practices in regards to management of sickle cell disease. The results are summarized in Table 5 followed by a narrative. From table 5, knowledge and practices of home based care were grouped into the themes of knowledge of sickle cell disease, and home care practices.

Theme 1: Knowledge in regards to sickle cell disease

This means possession of information, this assessed how the care givers understood sickle cell disease, the symptoms and the diagnosis process.

Sub theme 1: Symptoms of SCD

The symptoms of sickle cell disease included child falling sick frequently, having fever, joint pains, not having enough blood and swollen limbs like as stated below;

“.....I don't know what it means exactly, but what I know is that a child with sickle cell disease falls sick all the time, having fever with joint pains, swollen limbs, and having less blood in the body which leads to blood transfusion.....” [R3- A 46 year old male].

Sub theme 2: Diagnosis process

380 The diagnosis process included frequent hospital admissions and frequent blood transfusions
381 which prompted the test for sickle cell disease as stated below;

382 “.....*It was until my child was tested after frequent admissions in hospital with*
383 *blood transfusion, after results were out doctor told me that my child has sickle cell*
384 *disease.....*” [R3- A 46 year old male].

385 **Theme 2: Home based care practices in regards to the management of sickle-cell disease**

386 These included practices done by the care givers at home in the management of sickle cell disease.

387 **Sub theme 1: Tradition medicines**

388 The care givers used the local herbs in the name of making the sickle cell children not los blood
389 since they were prone to loss of blood however others never used them as stated below;

390 “.....*No I’ve never given any herbal medicine.....*” [R4,-A36 year old female].

391 “.....*Yes I do to prevent reduced blood in the body.....*” [R10-A 47 year old
392 male].

393 **Sub theme 2: Pain crisis management**

394 The care givers relied mainly on the hospital in the times of pain crisis as stated below;

395 “.....*I don’t treat him from home I bring him to hospital for management.....*”
396 [R10 - A 47 year old male].

397 **Sub theme 3: following medical advice**

398 Adherence to medical advice is very important in management of sickle cell disease.

399 The care givers reported to follow medical advice in terms of following the medical prescriptions,
400 ensuring that the child dresses warm clothes in cold weather, drinks enough water to hydrate the
401 body, and eating a balanced diet as stated below;

402 “.....*To provide warmth when too cold, putting on stockings and gumboots, giving*
403 *medication as prescribed in hospital, giving plenty of water.....*” [R2-A50 year old mal].

404 **Facilitators to home based practices**

405 These included things which promoted home based care practices; four subthemes emerged under
406 the main theme of facilitators to home-based practices. These includes; health worker support,
407 emotional and financial support, adherence to medical advice, and hospital support. The results for
408 facilitators to home-based practices are summarized in table 6:

409 **Sub theme 1: Health worker support**

410 There was health worker support in terms of guiding them during the hospital visits in terms of
411 treatment as stated below;

412 “.....*Yes because whenever he gets treatment/medication, he has no problem and health*
413 *workers are so welcoming and concerned about my child’s health.....*” [R5].

414 “.....*Yes when I bring him for review health workers teach me on how to take care*
415 *of my child with sickle cell disease.....*” [R1-A 42 year old male].

416 **Sub theme 2: Emotion and financial support**

417 Emotion and financial support is very important in the home based practices promotion, caregivers
418 reported to have got the financial and emotion support in terms of free interaction and no

419 discrimination at both school and home and also reported to get some financial support from the
420 family members as stated below;

421 “.....*My mother and my elder brother have been supporting me financially,*
422 *emotionally, socially and psychologically.....*” [R1, -A 42 year old male].

423 “.....*No my child is not discriminated both at home and school he interacts freely with*
424 *family members and friends at school.....*” [R1 -A 42 year old male].

425 **Sub theme 3: Adherence to medical advice**

426 The care givers adhered to home medical guidance in terms of following the prescribed drugs,
427 providing good nutrition to the sickle cell children, and hydrating them as stated below;

428 “.....*Giving medication as directed by the doctor, child putting on a sweater and*
429 *stockings when too cold, taking water but not too cold or from the fridge giving balanced*
430 *diet.....*” [R3- A 46 year old male].

431 **Sub theme 4: Hospital support**

432 The care givers reported hospital support in terms of availability of blood transfusion which
433 reduced immediate health risk as stated below;

434 “*But blood is always available and my child falling sick all the time has been a problem to me*”
435 [R3- A 46 year old male].

436 **Barriers to home based care practices in the management of sickle cell disease**

437 Four sub themes emerged including; health care gaps, financial constraints, transportation
438 difficulties, and frequent sickness burden. The results are summarized in Table 7 and later narrated:

439 **Sub theme 1: Healthcare system gaps**

440 Healthcare gaps were a great barrier to home based practices, this was through lack of essential
441 supplies like drugs, as stated below;

442 “.....I’ve gone through a lot because sometimes I come to hospital and there no drugs, fluid
443 giving sets, syringe, etc. and you have to buy of which I may lack money. But blood is always
444 available and my child falling sick all the time has been a problem to me.....” [R3 - A 46 year
445 old male].

446 **Sub theme 2: Financial constraints**

447 Home based care needed a lot of money to buy drugs, food and many other things, the care givers
448 reported lack of enough funds to buy the needed supplies needed in the management of sickle cell
449 disease as stated below;

450 “.....I’ve gone through a lot because the father to the child is in Sudan and I don’t
451 have money to take care of the child sometimes he sends money and sometimes doesn’t, the child
452 also falls sick all the time making me get worried of her condition sometimes no drugs in hospital
453 and you have to buy and yet no money.....” [R4 - A36 year old female].

454 **Sub theme 3: Transportation difficulties**

455 The caregivers come from far and always need transportation to the hospital for review and this
456 was seen as a barrier to home based practices since they needed guidance from the health workers,
457 they reported to lack money sometimes failing to meet scheduled dates as stated below;

458 “.....Yes very much so because health workers care so much about my child with
459 sickle cell disease and so concerned about my child.....” [R3- A 46 year old male].

Sub theme 4: Frequent sickness burden

The respondents reported that their children fall sick all most every time which burdens them as stated below;

“.....A lot the child may fall sick when I have no money to take her to hospital also getting so worried because of her sickness which is on and off all the time making life hard I can't do anything when she is sick.....” [R5- A 38 year old female].

Discussion

The findings of the study indicated that the caregivers' adherence to the home-based practices in the management of sickle cell disease was sub-optimal. This was demonstrated by only about half (51%) giving malaria prophylaxis without fail, only about 21.5% gave Penicillin without fail, 82% gave folic acid without fail and 72.5% avoided extreme temperatures without fail. In the qualitative arm of the study the home based care practices emerged as; use of traditional herbs which were thought to prevent the sickle cell children from blood loss, pain crisis management in which respondents relied mainly on the hospital. The findings of this study on the sub-optimal adherence to the home-based practices in the management of sickle cell disease aligns to findings from a study conducted in the same hospital (Mbale Regional hospital) that demonstrate that despite caretakers' high awareness in regards to sickle-cell disease, good knowledge and positive attitude towards the management of sickle-cell disease, their practices towards the management of sickle cell disease remains poor with only 43% giving their children pain killers and only 38% ensuring adequate hydration to prevent sickle-cell crisis [37]. However, some participants reported following medical advice where they gave medication as prescribed, fed children on a balanced diet, hydrated them and kept them warm in cold temperatures. This finding is consistent with that

in a study carried out at Jinja Regional Referral Hospital Uganda where the use of both convention medicine and herbal medicine in management of sickle cell disease was reported [51]. The findings are however, contrary to a study done in Ghana by Ajinkpang, Anim-Boamah [52] who reported good compliance to recommended home based measures like folic acid supplementation, penicillin prophylaxis, hydration, and maintaining normal body temperatures which were important in management of the disease [52]. The reason for this inconsistencies could be due to the differences in study setting and study designs.

The facilitators to home based care emerged in form of health worker support in which respondents reported to have got guidance from the health workers, financial and emotional support in which they reported getting some funds from their family members , and their children being able to interact freely with any one without discrimination, the sub theme of adherence to medical advice in terms of taking medication as prescribed, and lastly the sub theme of hospital support in terms of availability of the blood for the sickle cell children in order to avoid risks. According to findings of a scoping review by Druye, Amoadu [53], caregivers who received consistent support and guidance from healthcare providers were more likely to follow self-care protocols. This included regular follow-ups, personalized care plans, and accessible communication channels hence adhering to home based care practice. A study by Al Nasiri, Jacob [54] in Oman indicated that comprehensive educational programs that provided detailed information about SCD and its management significantly improved caregivers' ability to adhere to home-based care practices and consequently improved health related quality of life among children with sickle-cell disease. In regards to knowledge as a facilitator to adherence to home based practices, the findings illustrated that the participants had good knowledge in terms of symptoms of sickle cell disease, causes of the symptoms and the prevention of pain crisis in sickle cell disease. These finding were in line

505 with another study carried out in tertiary health centers in eastern Uganda which reported that the
506 participants knew pain was the commonest symptom (74.19%), jaundice (53.49%), and swelling
507 of limbs (59.95%) [55]. Good knowledge is important in the adherence to home based care
508 practices by the care givers as low knowledge by the care givers on the sickle cell disease has been
509 associated with complications due to poor adherence to the home based care practices , Ali Amour
510 and Jumanne [56].

511 The respondents demonstrated a number of barriers to home based care which included the cost of
512 the drugs in which 67% of the respondents reported it to be a problem for them. Difficulty getting
513 the medication was also reported to be sometimes a problem in 51% of the respondents. This was
514 in line with another study which reported that a great number of participants failed to adhere to
515 home based practices due to expensive drugs which they could not afford [57]. The barriers further
516 emerged in the qualitative arm in forms of transportation difficulties to the hospital in which
517 transport funds were needed being a problem as most of the guidance to home based care was from
518 the hospital, financial constraints in terms of buying drugs, health care system gaps in which there
519 was lack of drugs syringes and fluids at the hospital which required respondents to buy and lastly
520 falling sick burden as most the sickle cell children fell sick almost all the time and this was a big
521 burden to the care takers . In another study reported the barriers to be in categories of physical
522 opportunity which was mainly the cost of the drugs and other necessities, reflective motivation in
523 terms of sickle cell disease perception, and psychological capabilities in terms of forgetting to give
524 the drugs [58]. The findings are related to that of other studies across the globe [59] in which the
525 barriers were categorized into individual, interpersonal, provider, and socio-
526 environmental/organizational level. Individual-level barriers were lack of knowledge in self-
527 management and disease severity. Interpersonal level barriers were inadequate caregiver support

and competing life demands. Provider level barriers were limited provider knowledge, poor provider-patient relationship, Socio-environmental barriers were limited transportation, lack of insurance, administrative barriers, poor care coordination, and reduced access to care [59].

Impact of the study

This study sheds light on how caregivers manage sickle cell disease (SCD) at home for children receiving care at Mbale Regional Referral Hospital. The findings show that many caregivers struggle to consistently follow recommended home-based care practices, placing children at risk of avoidable pain crises, complications, and frequent hospital admissions. These challenges are often driven by everyday realities such as financial hardship, difficulties with transportation, gaps in the health system, and limited understanding of SCD. At the same time, the study highlights important sources of support that help caregivers cope, including guidance from health workers, support from health facilities, and financial, emotional, and social assistance from families and communities. Together, these findings emphasize the importance of family-centred care and strong health system support, especially in resource-limited settings. Improving caregiver education, strengthening social and financial support, and fostering closer engagement between health workers and families could ease the burden of care, improve disease management at home, and ultimately enhance the survival and quality of life of children living with SCD.

Strength and limitations of the study

The major strength of this study was the application of a mixed method research to understand the facilitators and barriers to the home-based practices in the management of sickle cell disease.

The limitation of this study is that it was a single centered study, however, the hospital being a regional referral hospital covering several districts of eastern Uganda increases the generalizability of the findings.

Conclusion

This study demonstrates that adherence to home-based care practices for the management of sickle cell disease among caregivers remains sub-optimal, exposing affected children to preventable complications and frequent illness episodes. Caregivers' ability to effectively manage SCD at home is strongly influenced by social, financial, and health system factors, including limited knowledge about the disease, financial constraints, transportation challenges, and gaps in health service support. At the same time, the presence of supportive health workers, access to hospital services, social and emotional support, and adherence to medical advice were identified as key facilitators of effective home-based care.

Recommendations

The health workers should continuously educate the caregivers in regards to home-based practices on the management of sickle cell disease.

There is urgent need to lobby for funds to support the caregivers of children with sickle cell disease. This will make it easy to access some the requirements in the home-based practices like buying medications like Fansidar, folic acid in case they are out of stock in the health facilities.

Health workers should also encourage sickle cell screening among the communities as a way of reducing children incidence of sickle cell disease.

Declarations

Ethical approval and consent to participate

Ethical clearance was obtained from the Busitema University faculty of Health sciences Research and Ethic committee with a reference number **BUFHS-2024-204** before data collection. Administrative approval was sought from the administration of Mbale regional referral hospital to authorize the researcher to interface with the respondents/participants. Informed written and verbal consent was obtained from each participant. The study participants were assured of confidentiality, no identifying information was collected, and data collected was kept securely and only accessed by authorized person. In this study we adhered to the ethical principles as prescribed by the Helsinki declaration [60, 61].

Clinical trial number

Not Applicable

Consent for publication

Not applicable.

Availability of data and materials

Data from this study will be made available by the corresponding authors on a reasonable request.

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Authors' contributions

C.W, P.A, L.VN.S, A.N, J.E, I.M, C.R and S.O conceptualized the study, C,SC and S.O participated in data collection and Analysis, C.SC and C.W, P.A, L.VN.S, A.N, J.E, I.M, C.R, R.N, IJS and S.O drafted the manuscript, , C.W and C.SC, A.N, F.O, E.N, J.K.O, P.A, L.VN.S, A.N, J.E, I.M, C.R, R.N, IJS and S.O revised the manuscript. All authors read and approved the final version of the submitted manuscript.

Table 1: Social demographic characteristics

Gender	n	%
Female	133	66.5
Male	67	33.5
Relationship to the child		
Mother	133	66.5
Father	67	33.5
Marital status		
Single	9	4.5
Married	174	87
Divorced	4	2
widowed	13	6.5
Occupation		
Civil servant	17	8.5
Self employed	176	88
Not employed	6	3.5
Total monthly family income		
Below 24,999 ug.shs	15	7.5
25,000 -49,999 Ug.shs	49	24.5
50,000-74,999 Ug.shs	73	36.5
75,000-100,000 Ug.shs	30	15.0
Above 100,000 Ug.shs	33	16.5
Religion		
Christian	127	63.5
Moslem	31	15.5
others	42	21.0
Tribe		
Mumasaba	19	9.5

Mugwere	112	56.0
Ateso	36	18.0
others	33	16.5
Age of the sickle cell child		
Below 5 years	57	28.5
6 -10 years	124	62.0
11 to 15 years	17	8.5
16 to 18 years	2	1.0
Variable	Mean	Standard deviation
Number of people in the family	4.97	1.45
Number of adults in the family	2.47	0.9
Times fallen sick in a month	1.23	0.639

596

597 **Table 2: Adherence to self-care management of sickle cell disease**

Adherence parameter	Never does it	sometimes	Always without fail	Mean	S.D	95% C.I	% Mean adherence
Takes prophylaxis Penicillin	89(44.5)	68(34)	43(21.5)	1.77	0.78112	1.66-1.88	59
Takes malaria prophylaxis	37(18.5)	59(29.5)	102(51.0)	2.328	0.773	2.2199-2.4365	77.61
Sleeps under insecticide treated net	08(4)	34(17)	158(79)	2.75	0.5185	2.677-2.8223	91.67
Avoids very warm or cold temperatures	8(4)	47(23.5)	145(72.5)	2.685	0.5452	2.6089-2.7610	89.5
Takes folic acid supplements	9(4.5)	26(13)	164(82)	2.7788	0.5138	2.7071-2.851	92.629
Total Adherence				2.46243546	0.42716	2.4162-2.5085	67.35

598 **Noted:** s.d- Standard deviation, CI- confidence Interval

599

600 **Table 3: Knowledge towards sickle cell disease**

Variable	Frequency	Percentage
Does your child attend scheduled appointments at the sickle cell clinic		
No	4	2.0
Yes	196	98.0
What type of sickle cell does your child have		
Hbss	4	2.0
Hbsc	4	2.0
Hbs - beta thalassemia	1	.5
Do not know	191	95.5
Joint pain is a symptom of sickle cell disease		
No	8	4.0
Yes	192	96.0
Swollen limb is a symptom of sickle cell disease		
No	46	23.0
Yes	154	77.0
Severe anemia is a symptom of sickle cell disease		
No	189	94.5
Yes	11	5.5
Malaria causes symptoms in sickle cell disease		
No	104	52.0
Yes	96	48.0
Anemia causes symptoms in sickle cell disease		

No	84	42.0
Yes	116	58.0
Coldness causes symptoms in sickle cell disease		
No	49	24.5
Yes	151	75.5
Medication prevents pain crisis in sickle cell disease		
No	24	12.0
Yes	176	88.0
Providing warmth in cold weather prevents pain crisis in sickle cell disease		
No	30	15.0
Yes	170	85.0
Hydrating prevents pain crisis in sickle cell disease		
No	75	37.5
Yes	125	62.5

601

602 **Table 4: Barriers to self-care management of sickle cell disease**

Variable	Never a problem	Sometimes a problem	Always a problem	Mean	S.D	95%C.I
Forgetting	104(52.0)	76(38)	20(10)	1.58	0.6677	1.482881 -1.66808
Difficulty getting medication	85(42.5)	102(51)	12(6)	1.63	0.5957	1.542-1.7077
Time constraint/busy	62(31)	95(47.5)	43(21.5)	1.905	0.720116546	1.542026 -1.707733
Cost of medication	65(32.5)	96(48)	38(19)	1.864	0.70831	1.799054 - 1.999214
Taste aversions/side effects	76(38)	78(39)	45(22.5)	1.84422	0.7659775	1.759894 - 1.957247
How difficulty to get Fansidar	105(51.0)	57(28.5)	41(20.5)	1.61	0.71446	1.506552 - 1.704582

How difficulty to get folic acid	102(51.0)	57(28.5)	41(20.5)	1.695	0.790633	1.581023 - 1.800023
How difficulty to get penicillin	97(48.5)	78(39)	25(12.5)	1.64	0.69482	1.538957 - 1.731685
How difficulty to get mosquito nets	100(50)	55(27.5)	45(22.5)	1.725	0.807860255	1.608579 - 1.83234
How difficulty to get portable water	85(42.5)	80(40)	35(17.5)	1.75	0.734984	1.643031 - 1.846919
How difficulty to administer fansidar	71(35.5)	89(44.5)	40(20)	1.845	0.73051	1.738054 - 1.940912
How difficulty to administer penicillin	96(48)	92(46)	12(6)	1.58	0.6045057	1.49118 - 1.659162
How difficulty to administer folic acid	88(44)	87(43.5)	25(12.5)	1.685	0.684189724	1.585092 - 1.774999
How difficulty to administer proguanil	94(47)	79(39.5)	27(13.5)	1.665	0.703740901	1.562641 - 1.757842
How difficulty to make child sleep under mosquito net	94(47)	67(33.5)	39(19.5)	1.725	0.76934123	1.613617 - 1.826924
How difficult to remember to administer fansidar	117(58.5)	64(32)	19(9.5)	1.51	0.664914	1.413658 - 1.597975
How difficulty to remember to administer penicillin	114(57)	74(37)	12(6)	1.49	0.60972	1.401035 - 1.570249
How difficulty to remember to administer folic acid	121(60.5)	60(30)	19(9.5)	1.49	0.664913944	1.393774 - 1.578057
How difficulty to remember to administer proguanil	127(63.5)	45(22.5)	28(14)	1.505	0.729821	1.40013 - 1.602195
How difficulty to remember make child sleep under mosquito net	128(64)	34(17)	37(18.5)	1.54271356	1.54271356	1.42947 - 1.648461
How difficulty to remember giving child portable water	128(64)	43(21.5)	27(13.5)	1.489898	0.7247	1.38524 - 1.586906

Grand Mean	1.489899 (0.3979)
Decision mean	2

603 NOTE: CI Confidence Interval, S.D-Standard Deviation

604 Table 5: knowledge on sickle disease and home-based practices to sickle cell disease
605 management

Themes	Sub themes	Meaning full units
Knowledge towards sickle cell disease	Symptoms of SCD: physical or mental sign/features which indicates a condition of the patient.	A child of sickle cell falls sick every time Joint pain, fever were some of the symptoms of SCD
	Diagnosis process: it's a process of identifying a disease basing on history, lab tests and examination.	Diagnosis was confirmed after frequent hospital admissions and blood transfusions.
Home based care practices	Traditional medicines	Used local herbs to reduced blood levels.
	Pain crisis management: it's a combination of medicine and physical therapies.	Relied on hospital for management during pain crises
	Following medical advice	Adhered to medication and ensured the child put on warm clothing in cold weather, drinks water, and eats a balanced diet.

607 **Table 6: Facilitators to self-care management of sickle-cell disease**

Theme	Sub theme	Meaning full units
Facilitators to home based practices	Health worker support: health education by health workers on the management of sickle cell disease while at home.	Received guidance from health workers during treatment appointments which enhanced their knowledge.
	Emotion and financial support	No discrimination was experienced by the child at home or school, promoting emotional well-being.
		Received some funds from the family members
	Adherence to medical advise	Caregiver followed prescribed medication schedules and provided proper nutrition and hydration to the sickle cell children
	Hospital support	Blood transfusion services are consistently available, reducing immediate health risks.

608

609 **Table 7: Barriers to home based care practices**

Theme	Sub theme	Meaning full units
Barriers to home based practices	Healthcare system gaps: discrepancy between recommended best practices and the care that's actually provided.	Needed supplies like drugs, were sometimes lacking at the hospital. So one can have the necessary drugs needed to use while at home
	Financial constraints	Caregivers lacked money to buy needed essential medications.
	Transportation difficulties	Care givers even missed appointments due to lack of money to transport them to the hospital.
	Frequent sickness burden	The child frequently falls sick which brings stress.

610

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