

## Retention-in-care and associated factors among adolescents living with sickle-cell disease in Kampala, Uganda

Patience Birungi<sup>1,\*</sup>, Francis Xavier Kasujja<sup>1,2</sup>, Aggrey Mukose<sup>1</sup>, Philip Kasirye<sup>3</sup>, Angela Nakanwagi Kisakye<sup>4</sup>, Juliet Kiguli<sup>5</sup>

<sup>1</sup>Department of Epidemiology and Biostatistics School of Public Health Makerere University, Kampala, Uganda, <sup>2</sup>Chronic Diseases and Cancer Theme, MRC/UVRI and LSHTM Uganda Research Unit, Entebbe, Uganda, <sup>3</sup>Department of Paediatrics and Child Health, College of Health Sciences, School of Medicine Makerere University, Kampala, Uganda, <sup>4</sup>Department of Health Policy Planning and Management, School of Public Health Makerere University Kampala, Uganda, <sup>5</sup>Department of Community Health and Behavioral Sciences, School of Public Health Makerere University Kampala, Uganda

### ABSTRACT

**Introduction:** Worldwide sickle-cell disease has been identified as the most widespread genetic disorder highest in low-income countries. In Uganda, approximately 25,000 babies are born with sickle cell disease every year. Mulago National Referral Hospital runs the oldest and largest specialized sickle cell clinic where over 17,000 people living with sickle cell disease are registered in care. This study assessed the proportion of adolescents with sickle-cell disease retained in care and associated factors. **Methods:** A cross-sectional study was conducted at Mulago National Referral Hospital. The study involved 309 adolescents enrolled on sickle-cell care from 2013 to 2017 who were living with sickle-cell disease. Retention was defined as having not missed a clinic appointment for at most six months. Modified Poisson regression analysis was used for this study. **Results:** A total of 309 adolescents from Kampala and Wakiso districts participated in the study. Their mean age was  $11.8 \pm 2.1$  years, majority of the respondents 86.1% (266/309) were aged 10-14 years, with 55.7% (172/309) living with both parents and 64.4% (199/309) residing in Kampala. Most 92.9% (289/309) were still in school, 74.1% (229/309) had at least primary education, and 53.1% (164/309) were female. Nearly 43.7% (135/309) were enrolled in care in 2013, and 87.4% (270/309) took less than two hours to reach the hospital. The retention level was 42% (130/309) 95% CI: 36.7, 47.7. Retention was associated with a positive attitude to keeping clinic appointments (aPR = 1.84; 95% CI: 1.02-3.30); not receiving enough medicines to last until next appointment, (aPR = 0.76; 95% CI: 0.58-0.99) and spending more than two hours traveling to the clinic, (aPR = 0.56; 95% CI: 0.32-0.99). **Conclusion:** Retention in SCD care was low among adolescents. Improving waiting times and having multi-month drug dispensing to last till next visit may improve retention in care.

**KEYWORDS:** Retention in care, Sickle cell, Adolescents, Uganda

### \*CORRESPONDING AUTHOR

Patience Birungi, Department of Epidemiology and Biostatistics, School of Public Health, Makerere University,  
Email: [billupatie@gmail.com](mailto:billupatie@gmail.com),  
ORCID: <https://orcid.org/0009-0000-0956-6893>

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## Introduction

Sickle-cell disease (SCD) affects over 250,000 children annually in over 40 countries all over the world [1-3]. People with SCD usually suffer from recurrent bacterial and malaria infections, body and bone pains and many other life-threatening complications [4]. The disease has been declared a major public health problem contributing considerably to under-five childhood mortality, especially in sub-Saharan Africa, due to its high prevalence and devastating effects [5]. Its burden is highest in countries with constrained resources and endemic malaria.

The global prevalence of sickle cell disease (SCD) is estimated to be between 20 and 25 million people [6], with approximately 12 to 15 million affected individuals residing in sub-Saharan Africa [7]. Nigeria leads with 24% of the population with SCD and a prevalence of about 20 per 1000 births [8, 9]. Under-five mortality from SCD is estimated at 75% in sub-Saharan Africa, accounting for up to 1 in 6 deaths and this proportion is projected to increase by 2050 [10, 11].

Uganda is among the countries with the highest reported prevalence of SCD where 25,000 children are born with the disease each year [8, 12]. Retention in care provides opportunities to access drugs and additional benefits through ancillary services, social support, and secondary prevention messages that can help patients navigate lifelong medication and complicated infections [13, 14]. It further involves health workers providing counselling and social support, assurance that people receive needed medical and supportive services and such retention goals are called for in managing sickle cell patients [15].

For healthcare units to achieve retention goals of persons with SCD, it will involve engaging the population, creating organized SCD programs and training health workers on sickle cell management [16]. Where these services are inadequate, patients may not return to the health unit for further care based on a social cognitive thinking influenced by social networks of friends and family members, especially where repeated clinic visits may not be perceived by patients and families as important in addressing pressing psycho-social needs [17].

One of the significant challenges faced by families with sickle cell patients is the financial burden [18]. Families often struggle to cover medical bills, travel costs, and the loss of parental productivity associated with caring for continually ill children [19]. Additionally, these families may face the added burden of caring for multiple family members with SCD [20].

Despite the improved life expectancy of an average of 45 years due to available therapies, many outcome goals remain unmet. This is not only because of the biological burden of end-organ failure or acute complications but also be due to the complex challenges arising from SCD

patients' interaction with the socio-ecologic system [21]. We assessed the factors associated with retention in care among adolescents aged 10-19 years living with SCD based on individual, environmental and health system factors that need to be in place to ensure continuous assessment of adolescents so that they are attracted to the clinic and stay in care.

## Methods

### Study site

This study was conducted at the largest specialized clinic for SCD treatment and research in Uganda. Established in 1968, the clinic is located at the Makerere University-affiliated Mulago National Referral Hospital in Kampala, the largest hospital in the country and the teaching hospital for the Makerere University College of Health Sciences. It is recognised as a centre of excellence for sickle cell care.

The SCD clinic provides free care to all age groups, including adults. It operates daily from Monday to Friday, focusing on routine care services. The clinic is staffed by pediatricians, nurses, a medical records officer, a counselor, volunteers, visiting professors, and rotating medical students.

To date, over 17,000 patients are enrolled at the clinic, with about 80% being children under 10 years of age. Patients are scheduled for follow-up appointments at intervals not exceeding three months to ensure continuity of care.

Loss to follow-up is defined as a patient missing a clinic visit for six months or more, as determined by a computer-based data system introduced in October 2010. This system has improved the tracking of patient care over the years, though still highly challenged with follow-up mechanisms due to limited resources.

The clinic serves an average of 50-80 patients daily, reflecting its critical role in delivering essential SCD services and addressing the healthcare needs of Uganda's population.

### Study design and population

This was a retrospective cross-sectional hospital-based study that used both primary and secondary data of adolescents aged 10-19 years from Kampala and Wakiso districts. Those who had not attended the clinic for more than 6 months were regarded as out of care. Secondary data was abstracted from the clinic records.

### Inclusion criteria

We included adolescents diagnosed with sickle-cell disease aged 10-19 years who were in and out of care and lived in Kampala and Wakiso districts.

### Exclusion criteria

We excluded adolescents whose medical records were missing key information for the study, such as age, sex, date of last and next clinic visit and those who were too ill to complete the study procedures.

### Sample size

The sample size was determined using the Leslie formula [22].

$$n = \frac{Z_{\alpha/2} \cdot P \cdot Q}{\delta^2}$$

Where

n=Required sample size

$Z_{\alpha/2}$  = 1.96 (standard normal value at  $\alpha=5\%$  level of significance) a

P = Estimated prevalence was 39%. This was the prevalence of no-show for appointments at a hospital based tertiary sickle cell ophthalmology clinic [23]

Q = 1- P

$\delta$  = Maximum error the investigator is willing to allow=5%

This sample size was further adjusted basing on the finite population of 579 using the formula

A , which generated a sample size of 340. Since the number of adolescents aged 10-19 years enrolled into sickle cell care clinic from 2013-2017 was known, a finite population (579) was used at 95% CI, prevalence= 39% and margin error= 5%. The calculated sample size was 366. Considering a non-response rate of 10%, the sample size was 406.

The final sample size used for analysis was 309. This was due to the inability to reach the 31 participants, primarily because of death and lack of phone contacts for their caretakers.

### Sampling

A clinic database was used to get phone contacts of the parents and guardians of the participants to come to the clinic for a face to face interview. This study was conducted from 1<sup>st</sup> May 2018 to 30<sup>th</sup> June 2018 and only adolescents who enrolled into care from January 2013-February 2017, both active and not retained in care were recruited. We chose this study period because it was the most recent and ensured that we captured the adolescent population needed for the study. Earlier timeframes would have included individuals who had already transitioned out of adolescence. Additionally, hospital records showed that many adolescents from previous years had passed on, making it difficult to obtain sufficient data on this group. These participants were selected using a systematic procedure. The sampling interval was determined by dividing the total number of adolescents enrolled in care from 2013 to 2017 (579) by the calculated sample size (340), resulting in an interval of 2. The first participant was selected randomly using simple random sampling, and then every second participant was selected thereafter, until the calculated sample size was reached.

### Study variables

This study adopted a comprehensive approach to investigate the multifaceted factors influencing retention in care among adolescents with sickle cell disease, recognizing that individual, environmental, and health system determinants collectively shape patient engagement and continuity of care.

### Dependent variable

The main outcome variable was retention in the care of adolescents living with SCD attending the SCD clinic at Mulago National Referral hospital. The clinic expects patients to visit at least once in every 3 months. In this study we considered adolescents who had not attended the clinic for more than 6 months since their last visit as not retained in care. Adolescents were asked the date of their last visit through self-report, and we used the records at the clinic to verify [14]

### Independent variables

#### Individual factors

Individual factors included the client's age, measured by the last birthday and recorded in complete years, as well as the district of residence, categorized as either Wakiso or Kampala. Gender was recorded as male or female, while level education was grouped into primary, secondary, or tertiary levels. Health literacy was assessed based on the number of sessions on sickle cell management attended at the clinic prior to receiving care. Parents' or caregivers' marital status was categorized as "Married" (married, living together, or in a stable relationship) or "Unmarried" (single, widowed, or separated). Additionally, parents' occupations and clients' adherence to clinic appointments were recorded.

#### Environmental factors

Environmental factors encompassed physical distance from the clinic and competing life activities such as schooling. These factors highlighted the broader living and social circumstances influencing access to and continuity of care.

#### Health system factors

Health system factors, included the convenience of operating hours, length of waiting time and the consistent presence of medical supplies, were examined as critical aspects of service delivery.

#### Data collection tool

We used a semi-structured questionnaire that was interviewer-administered to collect data on an individual's social demographic characteristics, environmental and

health system factors. A literature review was conducted to guide the research team and the data collection tool was designed and reviewed by the study team and SCD experts.

### Statistical analysis

Data were analyzed using statistical software Stata Version 14 to determine the proportion of adolescents aged 10-19 years that had been retained in-care at the sickle cell clinic in Mulago National Referral Hospital from January 2013 to February 2017. To assess the factors associated with the retention of adolescents aged 10-19 years in care at the sickle cell clinic in Mulago National Referral Hospital, a binary outcome variable retention in care was created. All adolescents who had missed clinic visits for six months or more were grouped as out of care and those who had not missed clinic visits for six months or more were grouped as retained in-care.

Descriptive statistical analysis of individual variables was conducted to assess the characteristics of the respondents. The univariate analysis was conducted to summarise categorical variables such as age group, educational level, marital status and sex to generate frequencies and proportions. Bivariate analysis was conducted using the Chi-square test to determine the association between the dependent and independent variables. All variables that met the cut-off criteria of p-value less than 0.25 were selected for analysis at the multivariate level. At the multivariate level, Modified Poisson Regression analysis was used to determine the association between the dependent and independent variables using a p-value of less than 0.05 at 95% confidence interval. The Modified Poisson Regression was used because the prevalence of dependent variable was more than 10% [24, 25]. Model building was achieved using a simultaneous modelling technique. A multicollinearity diagnostic was performed to eliminate variables in the models with the variance inflation factor (VIF) having a value of more than 10. If the p-value is > 0.05, we failed to reject the null hypothesis that the Poisson distribution provides a good fit.

### Ethical consideration

Ethical approval to conduct the study was obtained from Makerere University School of Public Health, Higher Degrees, Research and Ethics Committee (reference number MHREC 1082). We obtained institutional review and a waiver of consent from the Mulago National Referral Hospital Research and Ethics Committee and hospital administration for ethical and administrative clearance. Permission to conduct the study was also sought and granted by the head of the Sickle Cell Clinic department. Additionally, parents' permission to involve their children in the study was obtained, and assent and informed consent were sought accordingly from the study participants.

## Results

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### Participant's characteristics

The response rate of the study was 90.9% (309/340) and the mean age (SD) of the respondents was 11.8±2.1 years. Majority of the respondents, 266 (86.1%) were in the age group of 10-14 years. About three-fifths 172 (55.7%) lived with both parents and 199 (64.4%) of them lived in Kampala District. Almost all adolescents 287 (92.9%) were still attending school while 229 (74.1%) had attained at least a primary level of education and 164 (53.1%) were females. Of all those enrolled into care from 2013-2017, 135 (43.7%) of them were enrolled in the year 2013. Generally majority of the respondents 270 (87.4%) would take on average two hours or less to travel to the hospital. At least 214 (69.3%) of caretakers were married and 231 (74.8%) were informally employed (Table 1).

### Unadjusted analysis of factors and retention in sickle-cell care

Overall, the prevalence of retention in sickle cell care was 42.1% (130/309), [95% CI: 36.7 – 47.7]. The proportion of retention among respondents who considered keeping the appointment to be important was almost twice higher compared to peers who did not (cPR = 1.94; 95% CI: 1.08-3.50). However, lower prevalence of retention in sickle cell care was observed among: adolescents who did not perceive the need to remain in care (cPR = 0.49; 95% CI: 0.28-0.86) and those who said they were not given enough medicines to last until next appointment (cPR = 0.69; 95% CI: 0.52-0.90). Furthermore, the prevalence of retention in sickle cell care was significantly less among respondents who spent more than two hours travelling to the hospital (cPR = 0.51; 95% CI: 0.29-0.93) and those who spent more than two hours of waiting time at the clinic between arrival and receiving a service (cPR = 0.69; 95% CI: 0.52-0.90) as compared to their colleagues in other categories respectively. Proportion of retention in sickle cell care was significantly lower among those who perceived the medicine to be effective (cPR = 0.27; 95% CI: 0.07-0.90) and those who did not receive health education (cPR = 0.73; 95% CI: 0.54-0.98) than their peers respectively. No significant result was observed between retention in care and caretaker's occupation, perceived need for medicines, and easy access to clinic and staff availability (Table 2).

### Independent factors associated with retention in care of adolescents living with sickle cell disease

Keeping appointments was important, not receiving enough medicines and more than 2 hours average travel time to the clinic were significantly associated with retention of adolescents in sickle cell care after adjusting with all other factors. Those who perceived that keeping appointment was important were more likely to be retained compared to those who did not (aPR= 1.84;

95%CI: 1.0 2-3.30). Those not given enough medicines to last until next appointment were less likely to be retained compared to those who received enough (aPR = 0.76; 95% CI: 0.58-0.99). Similarly, those who travelled for more than two hours to reach the clinic were less likely to be retained in care compared to those who travelled for less than two hours (aPR = 0.56; 95% CI: 0.32-0.99).

## Discussion

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The low retention level observed in our study highlights the need for targeted methods to improve adherence to clinic appointments among adolescents. Other studies have reported slightly higher retention in care for sickle cell patients compared to this finding. For example, a study conducted in Tanzania from 2004 to 2014 on patterns and patient factors associated with loss to follow-up which revealed that 58.13% of the patients actively attended their clinic appointments. This could be attributed to the follow-up mechanism which included telephone call reminders for clinic appointments [27].

Similarly, a cohort study conducted between 2017 and 2018 in Mbujimayi, the capital city of the province of Eastern Kasai in the DRC, followed up children for two years and reported a retention level of 59%. This was due to the follow-up mechanisms put in place during the study period, such as providing free care to sickle cell patients to facilitate access to care and the implementation of medical follow-up [28]. Limited studies have focused on retention in care for sickle cell patients; therefore, many have been cohort studies on lost to follow-up, where patients were followed up for 2 to 5 years. The prevalence in this study is slightly lower compared to other studies, partly because follow-up mechanisms implemented in those studies enhanced retention [28, 29].

The plausible explanations for the low retention in our study included perceived low importance of keeping appointments, difficulty accessing the clinic due to long distances and treatment interruptions from running out of medication as reported in other studies on barriers to sickle cell care [30, 31]. Furthermore, in developed countries, similar challenges have been reported, such as difficulties in accessing necessary healthcare and other direct and indirect costs, including travel expenses and telephone calls to hospitals and all these can affect retention in care of sickle cell patients. These barriers may be particularly pronounced in our study population due to socioeconomic constraints, limited transportation options, and competing priorities such as school and household responsibilities[32, 33]. Additionally, adolescents may experience stigma or lack of parental support, further impacting their willingness or ability to attend clinic visits. Understanding these barriers is crucial for developing effective strategies to improve adherence and ultimately enhance retention in care.

Our study shows high proportions of retention among participants who considered keeping clinic appointment important, and this is consistent with other studies that have reported on the benefits of clinic attendance and adolescents' perceptions of appointment keeping [34]. Adolescents who recognize the importance of regular visits may be more likely to prioritize them, particularly if they associate attendance with better health outcomes[36]. Furthermore, studies have indicated that collecting prescriptions is often cited as the major reason for visiting a general practitioner, which aligns with our findings [36-39]. This suggests that emphasizing the necessity of medication refills and integrating health education into routine appointments could further improve retention.

Additionally, interventions that focus on reinforcing the value of consistent healthcare attendance, such as reminder systems and personalized counseling, have been shown to improve retention rates. Ensuring that adolescents understand the direct link between regular visits and long-term health outcomes can enhance their commitment to ongoing care [40].

A lower prevalence of retention in sickle cell care was observed among adolescents who did not perceive the need to stay in care however this was not statistically significant hence not an independently associated factor. Never the less, this finding corresponds with a study that revealed sick-cell patients, when feel well often do not see a reason to attend their scheduled appointment [37, 41]. This study observed low retention levels among respondents who reported spending more than two hours travelling to the hospital which may be attributed to travel expenses and the logistical burden of long-distance travel. Limited financial resources and transportation challenges could make frequent clinic visits difficult, ultimately affecting retention. However, this finding contrasts with a similar study that revealed that patients who lived more than 3 miles (approximately 5 kilometers) from the clinic kept significantly more appointments than those living 5 kilometers or less from the facility [42]. This discrepancy could be brought about by differences in healthcare access, availability of transportation options, or the perceived value of clinic visits among different populations. In some settings, individuals who travel long distances may be more motivated to attend appointments due to the limited availability of alternative healthcare facilities closer to their residences.

Interestingly, majority of the adolescents who were not given enough medicine to last until next appointment were less likely to be retained in care. This may be due to the inconvenience and burden of making repeated trips to the health facility, a factor highlighted in a study that identified recurrent healthcare visits as a barrier to retention [43]. Likewise, adolescents who perceived the medicine to be effective and those who did not received health education were also less likely to be retained in

care. This finding contrasts with a study [43] that reported patients with limited knowledge of their disease or difficulty navigating the healthcare system often experience inadequate pain control and poor healthcare outcomes. The reason for this could be that those who feel well-informed and perceive their medication as effective may not see the need for regular follow-ups leading to lower retention in care.

Similarly, low retention was observed among individuals who spent more than two hours waiting at the clinic before receiving a service compared to those with shorter wait times, though this was not statistically significant. This finding is consistent with a study in which adolescents expressed dissatisfaction with the prolonged waiting periods at the clinic [44]. A justification for this could be that extended waiting times may contribute to frustration and a sense of discouragement, ultimately leading to reduced adherence to appointments. Likewise, research from sub-Saharan Africa has highlighted extended wait times as a significant challenge that can undermine patient satisfaction and contribute to poor retention in care [45, 46].

Considering clinic appointment as important, not receiving enough medication to last until next appointment and travelling to the clinic for more than 2 hours were key predictors of retention in care in this study.

The study revealed that adolescents who considered keeping clinic appointment to be important were two times more likely to be retained into sickle cell care than those who did not. This is in line with a study [47] which reported that kept appointments was the only way to receive treatment and have better health. In addition, Cronin et al [48] pointed out that sickle cell disease requires comprehensive and life-long management.

Adolescents who did not receive enough medicines to last until next appointment were less likely to be retained into care. Studies by Green et al and Crosby et al [10, 37] concur with this finding where they noted that measures must be put in place for patients to get the required care including access to adequate medicines.

Data still revealed that adolescents spending more than 2 hours to travel to the clinic were at a greater risk of non-retention. This is seen in other studies which identified living a distance from the hospital as a hindrance in appointment keeping and to others transportation difficulties as a barrier to clinic attendance [36, 49].

Following the multivariate analysis, the good fit of the model was assessed using the Pearson chi-square test, which yielded a chi-square value of 0.591. In model evaluation, a lower chi-square value suggests that the observed data closely match the expected values under the fitted model, indicating a better fit. Since the chi-square

statistic is relatively low, this suggests that the model provides an adequate fit to the data [50].

### **Limitations of the study**

Participant identification was through clinic records followed by a phone call invitation to take part in the study. Adolescents whose caretakers known phone contacts were unavailable and those that missed key information (9.1%) were not able to participant in the study. At the time of the study there were no patient follow-up mechanisms due to limited resources such as airtime for making phone calls and other logistics for home visits.

We did not conduct a pilot study which may have helped standardize the data collection tools and improve their clarity. A pilot may have identified potential ambiguities and refined procedures, without it, some opportunities to optimize the study design may have been missed.

Furthermore, being a single hospital study in which majority of the participants are aged between 10-14 years (86.1%) may limit generalisability of the findings. However, we used both self-report and clinic records to determine retention levels which is a strength for this study. The recall bias that could have been introduced by self-report was controlled by verifying the information with clinic records.

### **Conclusion**

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The low retention rates observed in our study were largely attributed to perceived low importance of keeping appointments, treatment interruptions due to running out of medications, and difficulties in accessing the clinic due to long travel distances. These barriers reflect the challenges patients face in maintaining consistent care, as they often view appointments as non-essential, struggle with medication access, and find clinic visits burdensome. Addressing these issues through targeted interventions, such as adequate medication supply, improved patient education, and enhanced clinic accessibility, could help improve retention rates.

### **Recommendations**

In order to improve on the retention of adolescents into sickle cell care, this study recommends that the Ministry of Health needs to put emphasis on community sensitization and education programs geared towards the importance of keeping clinic appointments for sickle cell care treatment. The findings from this study maybe used by patients and caregivers to learn disease self-management strategies on how to access health care systems and how to make health care decisions to achieve improved health outcomes [51]. In addition, mechanisms should be put in place to ensure continuous supply of the medicines and supplies needed for the sickle cell clinic. A follow-up study on the fate of those who dropped out of care could be beneficial.

The clinic should consider designating specific staff or implementing a rotational schedule to provide weekend services, ensuring clients have access to critical care and reducing interruptions in service delivery.

The study further recommends that interventions for following up adolescents who are not active in care be put in place to ensure that they are retained. Measurers such as phone calls or text messages have been found to be effective [40, 52, 53]. Research is required to establish how identified factors associated with retention relate to actual retention in care of adolescents with SCD.

### Future studies

Future studies could focus on the continuum of care for individuals transitioning from pediatric to adult healthcare services, with particular emphasis on longitudinal assessments of retention rates and associated factors. Investigating the challenges and facilitators of seamless healthcare transitions could provide valuable insights for improving long-term outcomes for patients, especially those with chronic conditions.

### What is already known about the topic

- Studies report clinic retention rates of 58.13% among sickle cell patients [14].
- Adolescent transition rates to adult care are 42%, with fear of a new provider as a barrier [46].
- Similar studies show that competing activities contribute to missed appointments [25].

### What this study adds

- This study widens understanding of the barriers of retaining adolescents into sickle cell care at Mulago National Referral Hospital and gives highlights of what stakeholders may do to improve retention in care.

### Competing Interest

The authors declare no competing interests. One of the authors, Angela Kisakye, is an editor of the Journal of Interventional Epidemiology and Public Health; however, she was not involved in the editorial processes and decision for this manuscript.

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staff. We acknowledge all the study participants and research assistants.

### Authors' contributions

PB conceived and led the design of the study protocol, data collection, data analysis and initial interpretation of data. She wrote the first draft of the paper and took part in the subsequent revisions. She was also responsible for submission of the paper. AM and PK, made substantial contributions to the conception and design of the study. PK and FXK contributed to the data collection process by reviewing the data collection tool. FXK, ANK and JK worked on data interpretations and were involved in the drafting of the manuscript. All authors revised the paper for important intellectual content and read and approved the final version.

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<b>Table 1: Distribution of participants' characteristics (N = 309)</b>		
<b>Variable characteristics</b>	<b>Frequency</b>	<b>Percent</b>
<b>District of residence</b>		
Kampala	199	64.4
Wakiso	110	35.6
<b>Age of respondents (years)</b>		
10–14	266	86.1
15–17	36	11.7
18–19	7	2.2
<b>Still schooling</b>		
Yes	287	92.9
No	22	7.1
<b>Education level</b>		
No education	6	1.9
Primary	229	74.1
Secondary	74	24.0
<b>Sex of respondents</b>		
Female	164	53.1
Male	145	46.9
<b>Caretaker marital status</b>		
Married	214	69.3
Single parents	69	22.3
Divorced/separated	26	8.4
<b>Caretaker's occupation</b>		
Formal Job	78	25.2
Informal Job	231	74.8
<b>Average time to reach clinic</b>		
≤ 2 hours	270	87.4
> 2 hours	39	12.6
<b>Whom do you live with</b>		
Both parents	172	55.7
Only mother	94	30.4
Only father	13	4.2
Grandmother/father	13	4.2

Sibling	17	5.5
<b>Year of enrolment at clinic</b>		
2013	135	43.7
2014	59	19.1
2015	37	12.0
2016	40	12.9
2017		
<b>Retention in sickle cell care</b>		
Yes	130	42.1
No	179	57.9
<i>N = total number of respondents.</i>		

<b>Table 2: Unadjusted prevalence ratios of factors and retention in sickle cell care</b>				
<b>Variable characteristics</b>	<b>Retention in Sickle Cell Care</b>		<b>Unadjusted PR (95% CI)</b>	<b>P-Value</b>
	<b>Yes n (%)</b>	<b>No n (%)</b>		
<b>Caretaker's occupation</b>				
Formal job	38 (48.7)	40 (51.3)	1	
Informal job	92 (39.8)	139 (60.2)	0.82 (0.62-1.08)	0.155
<b>Education level</b>				
No education	3 (50.0)	3 (50.0)	0.82 (0.36-1.85)	0.636
Primary	94 (41.0)	135 (59.0)	0.89 (0.38-2.07)	0.790
Secondary	33 (44.6)	41 (55.4)	1	
<b>Sex</b>				
Female	65 (39.63)	99 (60.37)	1.33 (0.87-1.47)	0.356
Male	65 (44.83)	80 (55.17)	1	
<b>Marital status</b>				
Married	88 (41.12)	126 (58.88)	0.99 (0.71-1.36)	0.937
Single	28 (40.58)	41 (59.42)	1.31 (0.88-0.48)	0.176
Divorced	14 (46.15)	12 (46.15)	1	
<b>Perceived effectiveness of medicine</b>				
Yes	128 (43.8)	164 (56.2)	1	
No	2 (11.8)	15 (88.2)	0.27 (0.07-0.90)	0.049
<b>Perceived need for medicines</b>				
Yes	121 (43.4)	158 (56.6)	1	
No	9 (30.0)	21 (70.0)	0.69 (0.39-1.21)	0.200
<b>Receive health education</b>				
Yes	90 (46.9)	102 (53.1)	1	
No	40 (34.2)	77 (65.8)	0.73 (0.54-0.98)	0.035
<b>Perceived need to remain in care</b>				
Yes	120 (45.5)	144 (54.5)	1	
No	10 (22.2)	35 (77.8)	0.49 (0.28-0.86)	0.013
<b>Perceived importance of keeping appointment</b>				
Not important	9 (23.1)	30 (76.9)	1	
Important	121 (44.8)	149 (55.2)	1.94 (1.08-3.50)	0.027
<b>Satisfied with services</b>				

Yes	124 (44.1)	157 (55.9)	1	
No	6 (21.4)	22 (78.6)	0.49 (0.24-1.00)	0.050
<b>Easy access to clinic</b>				
No	95 (45.7)	113 (54.3)	1	
Yes	35 (34.7)	66 (65.3)	0.76 (0.56-1.03)	0.078
<b>Waiting time</b>				
≤ 2 hours	92 (47.7)	101 (52.3)	1	
> 2 hours	38 (32.8)	78 (67.2)	0.69 (0.51-0.93)	0.014
<b>Time travelled to clinic</b>				
≤ 2 hours	121 (44.8)	149 (55.2)	1	
> 2 hours	9 (23.1)	30 (76.9)	0.51 (0.29-0.93)	0.027

**Table 3: Adjusted prevalence ratio of factors and retention in care of adolescents living with sickle cell disease**

Variable characteristics	Retention in sickle-cell care		Unadjusted PR (95% CI)	Adjusted-PR (95% CI)
	Yes n (%)	No n (%)		
<b>Caretaker's occupation</b>				
Formal job	38 (48.7)	40 (51.3)	1	1
Informal job	92 (39.8)	139 (60.2)	0.82 (0.62-1.08)	0.85 (0.64-1.11)
<b>Perceived effectiveness of medicines</b>				
Yes	128 (43.8)	164 (56.2)	1	1
No	2 (11.8)	15 (88.2)	0.27 (0.07-0.90)	0.39 (0.10-1.43)
<b>Receive health education</b>				
Yes	90 (46.9)	102 (53.1)	1	1
No	40 (34.2)	77 (65.8)	0.73 (0.54-0.98)	0.82 (0.62-1.09)
<b>Need to remain in care</b>				
Yes	120 (45.5)	144 (54.5)	1	1
No	10 (22.2)	35 (77.8)	0.49 (0.28-0.86)	0.69 (0.39-1.21)
<b>Perceived importance of keeping appointment</b>				
Not important	09 (23.1)	30 (76.9)	1	1
Important	121 (44.8)	149 (55.2)	1.94* (1.08-3.50)	1.84* (1.02-3.30)
<b>Satisfied with services</b>				
Yes	124 (44.1)	157 (55.9)	1	1
No	6 (21.4)	22 (78.6)	0.49 (0.24-1.00)	0.74 (0.37-1.47)
<b>Easy access to clinic</b>				
No	95 (45.7)	113 (54.3)	1	1
Yes	35 (34.7)	66 (65.3)	0.76 (0.56-1.03)	0.93 (0.68-1.26)
<b>Given enough medicine until next appointment</b>				
Yes	78 (49.7)	79 (50.3)	1	1
No	52 (34.2)	100 (65.8)	0.69** (0.52-0.90)	0.76* (0.58-0.99)
<b>Waiting time</b>				
≤ 2 hours	92 (47.7)	101 (52.3)	1	1
> 2 hours	38 (32.8)	78 (67.2)	0.69 (0.51-0.93)	0.81 (0.61-1.08)
<b>Average time to travel to clinic</b>				
≤ 2 hours	121 (44.8)	149 (55.2)	1	1
> 2 hours	9 (23.1)	30 (76.9)	0.51* (0.29-0.93)	0.56* (0.32-0.99)
<b>Model fitness (x2)</b>				<b>0.591</b>
<i>PR = prevalence ratio, CI = confidence interval, n = frequency, **p&lt;0.01 &amp; *p&lt;0.05.</i>				