

Knowledge, Attitudes and Practices about Sickle Cell Anemia in Tharu Communities of Kailali, District of Nepal

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Abstract

Introduction:

Sickle cell anemia (SCA) is a hereditary blood disorder where red blood cells take on a sickle shape, impairing oxygen transport and causing chronic pain, organ damage, and other complications. In Nepal, the disease is disproportionately prevalent among the indigenous Tharu community, especially in the Kailali district. Despite its health burden, awareness, diagnosis, and management remain inadequate, particularly at the grassroots level. This study aimed to assess the knowledge, attitudes, and practices (KAP) related to SCA among the Tharu community in Kailali.

Methodology:

A mixed-method cross-sectional study was conducted. Quantitative data were collected from 386 Tharu participants using structured questionnaires. In addition, seven key informant interviews (KIIs) with local health workers and officials provided qualitative insights. Multistage random sampling was employed for the survey, while purposive sampling was used for the interviews. Data were analyzed using SPSS version 25 and Microsoft Excel 2010.

Results:

Although almost all (99.5%) of participants showed a favorable attitude toward SCA, less than half (47.2%) had good knowledge, and only just above one in every five (22.5%) practiced preventive measures such as screening or counseling. Preventive practices were significantly associated with factors like age (33–48 years), secondary education, rural residence, and household income above NPR 25,000. Interestingly, rural participants were more engaged in preventive actions than urban counterparts.

Qualitative findings revealed low community awareness, generational knowledge gaps, and moderate stigma especially around marriage. Barriers included limited health infrastructure, a lack of trained staff, irregular screening, and insufficient policy support. Nonetheless, community leadership, existing screening programs, and government schemes like the Poor Citizen Fund present opportunities for improvement.

Conclusion:

Despite favorable attitudes, the Tharu community in Kailali exhibits poor knowledge and even lesser proportion of them practice SCA prevention. Knowledge intervention considering SCA attitudes may improve SCA screening and thereby reducing the disease burden.

Introduction

Sickle-cell disease is among the most prevalent severe monogenic disorders globally[1]. The disease's pathophysiology is primarily driven by hemoglobin polymerization, which causes erythrocytes to become rigid and leads to Vaso-occlusion. However, the roles of chronic anemia, hemolysis, and vasculopathy are also well-recognized in its progression[2]. Sickle cell trait involves having one copy of the altered hemoglobin gene and typically does not cause significant clinical symptoms. In contrast, sickle cell disease involves two copies of the altered hemoglobin gene, leading to the rapid destruction of red blood cells (RBCs), resulting in chronic and severe anemia with consistently low hemoglobin levels and noticeable clinical symptoms[3].

Globally, sickle cell anemia is widespread, with an estimated 5% of the world population carrying the gene responsible for hemoglobinopathies. In Africa, about 20,000 infants are born annually with the sickle cell anemia gene. Sickle-cell anemia is most commonly found in people with ancestry from sub-Saharan Africa, India, Saudi Arabia, and Mediterranean countries. Migration has increased the occurrence of the gene in the Americas[4]. Among children over five years old, sickle cell ranks 40th in global cause-specific mortality[5]. A meta-analysis estimated that sickle cell disease accounts for 7.3% (4.03–10.57%) of under-5 mortality in Africa[6]. In Nepal, a study conducted from July 2016 to December 2018 using data from five testing sites found that sickle cell disease was more prevalent in Provinces 5, 6, and 7, with the highest proportion recorded in Province 6 (70.0%) and no cases reported in Province 3 (0.0%)[7].

Despite this burden, in the context of Nepal, there is a lack of comprehensive prevalence studies and awareness about sickle cell disease, especially among the Tharu community[8]. Many individuals remain unaware of their sickle cell status, complicating efforts to prevent the genetic transmission of the disease. Furthermore, lack of knowledge, negative community and family attitudes, and inadequate health practices hinder the health outcomes of patients and the effectiveness of service delivery systems[9].

There is a clear research gap in understanding the knowledge, attitudes, and practices (KAP) regarding sickle cell disease among high-risk communities such as the Tharu[10]. This gap limits the development of effective policies and interventions to reduce the disease burden and improve health outcomes[11]. Monitoring sickle cell disease is important for at least three Sustainable Development Goal (SDG) reduction targets: maternal mortality (SDG 3.1), neonatal and under-5 mortality (SDG 3.2), and premature mortality due to non-communicable disease (SDG 3.4). This is because sickle cell disease is highly prevalent in historically malaria-endemic regions of Africa, the Middle East, the Caribbean, and South Asia[12]

Addressing this gap, the present study aims to explore the knowledge, attitudes, and practices related to sickle cell anemia among the Tharu community. The findings will help inform policymakers and stakeholders to formulate targeted policies and interventions for the prevention and management of sickle cell anemia in affected areas.

Materials and Methods

Study design and setting

The study was conducted in Kailali District, located in the Sudurpaschim Province (Far western Province) of Nepal. The district comprises one sub-metropolitan city, seven municipalities, and five rural municipalities. Approximately 36% of Kailali's total population belongs to the Tharu community. The study was carried out in two municipalities of Kailali District: Janaki Rural Municipality and Tikapur Municipality. Janaki Rural Municipality has a Tharu population of 59.8%, while Tikapur Municipality has 39.4%. The study, conducted from October 2024 to May 2025, employed a mixed-method approach following a convergent parallel design.

Study participants and sampling procedure

Participants aged 18–60 years from two study areas of Kailali district were recruited as study participants. The inclusion criteria for the study participants were aged 18–60 years residing in the study area, and those who belong to Tharu ethnic group. While the exclusion criteria were People who did not belong to the Tharu ethnic group and had intermarried with another caste group.

A multistage random sampling technique was used for the study. Out of 13 municipalities, 2 were excluded because they did not have a Tharu population in Kailali district. One rural municipality and one urban municipality were selected by simple random sampling. Wards from each selected municipality were chosen based on the proportion of the Tharu population in the ward relative to the municipality. The list of village was obtained from the selected wards of the chosen municipality. The total sample size was allocated proportionally to each municipality and ward. Study participants were selected from the chosen village by simple random sampling, and face-to-face interviews were conducted. Qualitative data were collected using purposive sampling.

Sample size calculation

The sample size was determined using Cochran's formula by considering the assumption of a 50% proportion, taken due to lack of study in the local setting about KAP of sickle cell anemia, 95% confidence interval, 5% margin of error, with infinite population of Tharu in Kailali district, and Cochran's formula (William G. Cochran, 1977) for calculating sample size when the population is infinite;

$$n^{\circ} = \frac{z^2pq}{d^2}$$
 with other values conventionally as $Z = 1.96$ (for 95% CL), $p = 0.5$, $q = 0.5$, allowable error (d) = 5% = 0.05. We obtained 385 for each municipality; we divided total sample group into equal number considered as 193 for each municipality, and final sample sized took 386.

For qualitative sample, KII were selected from the study site health facility based on the principle of saturation.

Study variables

The dependent variable in this study was preventive practice about sickle cell anemia and independent variables were socio-demographic characteristics (age, sex, marital status, occupation, educational level, place of residence, monthly family income), knowledge about sickle cell anemia and attitude about sickle cell anemia.

Study Instrument

For data collection regarding knowledge, attitudes, and preventive practices, a structured questionnaire was adopted from previously published studies [13–16]. Permission to use the instruments was obtained by formally requesting them from the respective authors via email. The questionnaire consisted of four sections: Section A covered the respondents' socio-demographic characteristics; Section B assessed knowledge about sickle cell anemia; Section C measured attitudes toward sickle cell anemia; and Section D assessed preventive practices related to sickle cell anemia.

The questionnaire was further modified to ensure its appropriateness and relevance to the study context and was reviewed by experts to establish content validity in accordance with the study objectives. The internal consistency of the questionnaire was assessed using Cronbach's alpha, which yielded a value of 0.80, indicating good internal consistency. The original research instruments were developed in English, translated into Nepali, and then back-translated into English to ensure linguistic accuracy and conceptual equivalence.

Operational definitions

Ethnic Tharu people

An indigenous Tharu ethnic group who live in the Kailali district of Nepal.

Preventive Practice

Respondent who has tested their sickle cell status and knows their disease status.

Knowledge Score: Nineteen items assessed participants' knowledge of sickle cell disease, covering symptoms, inheritance, and prevention. Each correct response earned one point; incorrect or “don't know” responses earned zero. Scores were converted to percentages: <60% indicated poor knowledge, 60–79% moderate, and 80–100% good knowledge[17].

Attitude Score: Attitudes toward people with SCD were assessed using ten questions, each with five-point Likert scale options (strongly agree to strongly disagree). Responses were scored and converted to percentages based on Bloom's criteria: <60% indicated poor attitude, 60–79% moderate, and 80–100% good attitude.

Data collection

Data were collected through face-to-face interviews using a structured questionnaire from Tharu people who had been residing in the study area for at least six months. The data collection tool was an interview schedule. Data were gathered in three different sections: the first focused on demographic characteristics, the second on assessing knowledge, attitude, and third on preventive practice about sickle cell anemia. The duration of each interview was between 15 and 20 minutes. To ensure the quality of the work, the entire data collection process was closely supervised by the supervisor as needed.

For qualitative: - Data were collected from service providers and health managers at seven sites located within the study area using a Key Informant Interview (KII) guideline.

Data Analysis

The data was analyzed by using the statistical software namely SPSS (Statistical Package for Social Science) version 22. Corrected data was exported to SPSS. Descriptive statistics was performed for the description of the characteristics of the respondents and presented using texts, tables, and graphs. A chi-square test was performed for all variables to check the assumptions. While, bivariate and multivariate techniques will be applied to identify correlates of KAP. Bivariate analysis was done and all explanatory variables associated with sickle cell related preventive practices with statistical significance at 95% confidence level and $P < 0.05$ was identified and entered into multivariate logistic regression model. Both crude and adjusted odds ratios with the corresponding 95% confidence interval was calculated to measure the strength and presence of association between the preventive practices and its associated factors.

Results

The findings were calculated in frequency and percentage. Similarly, the result was presented in narrative forms and the data was presented in tabular forms.

Descriptive characteristics

The majority (48.7%) of participants were aged 18–32 years followed by aged 33–48 years (38.1%). The median age of the respondents was 33 and the interquartile range was 42 years. Majority of the respondents (61.4%) were female and most of the respondent (92%) were Hindus while few were Christian (7.5%) and other (0.5%). The majority (42.5%) of respondents had completed education up to the secondary level (9–12), while (27.7%) had achieved basic education (1–8). Likewise, most (33.4%) of the respondents were involved in agriculture followed by 23.8% of respondents were homemaker. Regarding marital status, most of (86.7%) the respondent was married followed by (11.7%) were single. (Table 1)

Table 1
Socio-demographic characteristics of the participants

Characteristics	Frequency (n = 386)	Percentage (%)
Age group (Years)		
18–32	188	48.7
33–48	147	38.1
49–60	51	13.2
Md (IQR): 33 (42)		
Gender		
Female	237	61.4
Male	149	38.6
Educational Status		
Non formal education	79	20.5
Basic Education	107	27.7
Secondary Education	164	42.5
Higher Education	36	9.3
Marital Status		
Never Married	45	11.7
Married	338	87.6
Widowed	3	0.8
Occupational Status		
Homemaker	92	23.8
Agriculture	129	33.4
Labor	29	7.5
Business	67	17.4
Service	35	9.1
Student	34	8.8
Religion		
Hindu	355	92.0
Christian	29	7.5

Characteristics	Frequency (n = 386)	Percentage (%)
Age group (Years)		
Other	2	.5

Respondent Family and community related information

Among the total respondents (44.3%) of respondents belong to nuclear families followed by (38.1) joint family. Similarly, half of the (50.5) respondent's household monthly income was less than 25000NPR. Regarding health insurance just more than one-third (35.2%) of household were enrolled in health insurance (Table 2).

Table 2
Respondent family and community related information

Characteristics	Frequency (n = 386)	Percentage (%)
Household's monthly income (NPR*)		
≤ 25000	195	50.5
>25000	191	49.5
Md (IQR):25000 (395000)		
Family Type		
Nuclear	171	44.3
Joint	147	38.1
Extended	68	17.6
Health Insurance		
Yes	136	35.2
No	250	64.8
Place of Residence		
Urban	193	50.0
Rural	193	50.0
*1NPR = 0.0073 (as per 10th June 2025)		

Socio-demographic information of key informant

Among the participants involved in the Key Informant Interviews (KIIs) with health workers, the majority were male (86%). The roles held by these participants included Health Post In-Charge/Focal Person (28.5%), Chief of the Health Section at Tikapur Municipality and Chief of Janaki Rural Municipality

(28.5%), Focal Person at the Health Office Kailali (14%), and Focal Person at Seti Provincial Hospital and Tikapur Hospital (28.5%) (Table 3).

Table 3
Socio-demographic characteristics of KII

Character	Categories	KII with health workers (n = 7)
Gender	Male	6
	Female	1
Participants	Health Post /UHC in-charge	2
	Health section chief	2
	Focal person	3

Sickle cell Anemia related knowledge, attitude and practices

Nearly half (47.2%) of participants had moderate to good level of knowledge about sickle cell anemia. (Table 4)

It is also supported by qualitative findings one of the key informants from provincial hospital said that:-

"They don't really have much knowledge... only know it as 'sickle'... don't have any further understanding... counseling aspect is still lacking... usually come saying hands, feet, and joints hurt, or jaundice."— KII1 (facilitator, provincial hospital)

Moreover another KII from district hospital said that:-

"There is definitely a lack of knowledge-there is some level of awareness, but not everyone has the same understanding. Some people have now heard about sickle cell anemia, but they still lack complete knowledge about how it spreads or what to do to protect themselves."-KII 5 (Physician, district hospital)

Moreover another KII from local level health facility said that:-

"Most people in the Tharu community still lack knowledge about sickle cell anemia. Those who do have some understanding usually have someone in their family or neighborhood who is affected, so they have basic awareness. Otherwise, about 70–80% of Tharu individuals either have very limited knowledge or none at all. These days, they might have a vague idea, but they still don't know how it spreads or what the symptoms are. Many people have just heard that it's a disease that exists in the community."-KII 7 (In-charge of UHC)

Attitude: - About two-third of respondents (73.1%) possessed good attitude towards sickle cell Anemia, where as 26.4% participant had moderate level of attitude towards sickle cell Anemia. (Table 4)

It is also supported by the qualitative findings one of the KII from provincial hospital said that:-

*"It's not so much discrimination, but now many of them are coming forward openly, saying, 'I have sickle cell, please give me treatment.' Some are a little hesitant, especially those who are more educated; they are somewhat hesitant. For example, there was a person from Tikapur, a bachelor's degree holder, who was studying for a master's degree. They themselves didn't come but sent a guardian to register for them. The report was fine, and they registered and sent it."*KII1(facilitator, provincial hospital)

Moreover another KII from Janaki rural health section said that:-

*"Many people don't know about sickle cell. For those who do know, they consider it to be very dangerous, as it is hereditary. Because of this, even when they get married, they are hesitant. The educated people understand that it's a risk, so they try to avoid marriage if they find it in their partner."*KII 3(health section chief, Janaki RM)

Moreover another KII from Urban health center said that:-

*"In terms of stigma and discrimination from family or society, that doesn't seem to be very prevalent. However, the patients themselves-those affected-seem to feel shame or fear that others might say something or treat them differently if they find out about the disease. That fear prevents them from opening up."*KII7(In charge, UHC)

Informants reported that while overt discrimination is limited, mild to moderate stigma around sickle cell anemia persists. Some patients openly seek treatment, but others especially the more educated may feel hesitant or conceal their condition due to fear of social judgment. Concerns about hereditary risk also influence marriage decisions, with individuals avoiding partners known to carry the disease. Internalized fear and shame among patients often prevent them from openly discussing their condition.

Only 1/3 (22.5%) participant follows preventive practice whereas about 2/3(77.5%) did not follow preventive practice regarding Sickle cell Anemia (Table 4).

Which is also supported by the qualitative findings one of the KII from health section from urban municipality said that:-

*"Given that some communities are far from services, how can we include them in sickle cell services, counseling, and awareness programs? ... When we have budget and program opportunities, we try to reach out to communities that are more isolated or in poverty. We assess where the need is greatest and try to organize activities in those areas."*KII 4(health section chief, Urban municipality)

Moreover KII from district health office stated that:-

"There isn't a specific awareness program on sickle cell in our rural municipality's regular schedule. However, the District Health Office sometimes conducts programs related to free testing for sickle cell at various sites. These are mostly focused on the Tharu community. Apart from distributing some pamphlets or materials, I haven't seen any large-scale awareness campaigns being run."-KII 6(Focal person, District health office)

Moreover KII from urban health center from urban municipality said that:-

"No, many people are still missing out. We haven't been able to bring everyone under our coverage, and we haven't informed all the current patients about the availability of this medicine at our center. Initially, we didn't even have data on how many people in our ward are affected by sickle cell. Without that data, it's hard to inform people."-KII 7(In charge from UHC)

Sickle cell testing efforts are limited and mainly conducted through occasional programs by the District Health Office, often targeting the Tharu community. There is no regular or systematic testing schedule, and many remote areas remain unreached due to funding constraints and lack of data on affected individuals (Table 4.)

Table 4
Sickle cell Disease related knowledge, attitude and preventive practice status of participants

Characteristics	Frequency (n = 386)	Percentage (%)
Knowledge Level		
Good	22	5.7
Moderate	160	41.5
Poor	204	52.8
Attitude Level		
Good	282	73.1
Moderate	102	26.4
Poor	2	0.5
Preventive Practices		
Yes	87	22.5
No	299	77.5

Analysis of factors associated with the Preventive Practice of Sickle Cell in logistic regression analysis

With reference to adjusted odds ratios, The adjusted odds ratio reveal that 33–48 year age group of the participant were 2.2 times (aOR 2.210, 95% CI: 1.217–4.013) more preventive practice compared to below 33 years participants. Likewise, in the municipality, participant who had secondary level of education were 3.8 times more likely to followed preventive practice compared to non-formal educated participant (aOR 3.893, 95% CI: 1.602–9.460).

Also, the odds of followed preventive practice was two times (aOR 2.805, 95%CI: 1.597–4.927) higher among the rural municipality participants compared to participant of urban municipality Likewise, participants who has moderate level of knowledge had (aOR 2.258, 95% CI: 1.305–3.907) 2.2 time more good preventive practice compare to the participant who had good level of knowledge. (Table 5)

Table 5
Multivariate regression of Sickle Cell Anemia related practices

Variables	UOR	95% CI	p-value	AOR	P-value	95%CI
Age						
18–32	1			1		
33–48	2.083	1.239–3.449	0.006*	2.210	0.009*	1.217–4.013
49–60	1.341	0.622–2.890	0.454	2.203	0.114	0.828–5.862
Education						
Non formal education	1			1		
Basic Education	1.788	0.817–3.909	0.146	1.881	0.152	0.793–4.461
Secondary Education	2.558	1.245–5.257	0.011*	3.893	0.003*	1.602–9.460
Higher Education	0.773	0.228–2.615	0.678	0.975	0.970	0.249–3.821
Income						
≤ 25000	1			1		
> 25000	1.710	1.053–2.728	0.030*	1.247	0.426	0.724–2.146
Place of Resident						
Urban	1					
Rural	3.667	2.16–6.221	< 0.001***	2.805	< 0.001***	1.597–4.927
Sickle cell knowledge						
Poor	1			1		
Moderate	2.636	1.580–1.580	< 0.001*	2.258	0.004	1.305–3.907
Good	2.707	1.019–7.192	0.046*	2.185	0.140	0.774–6.166
*Significance level, 0.05; **0.01, ***0.001; P values in bold are significant						

Discussion

The study showed a good proportion of community attitude (nearly two-third with moderate-to-good), however, only nearly a half with moderate-to-good community knowledge, and even poor practice proportion (less than one in four practicing for SCA prevention). Along with this knowledge-attitude-practice gap, mainly attitude-practice gap, we further discuss the factors that influence SCD prevention practices, mainly knowledge, and socio-demographic ones. Our study revealed that only 5.7% of participants demonstrated a good level of knowledge about sickle cell disease (SCD), while 41.5% had a

moderate understanding, and the majority (52.8%) lacked sufficient knowledge of the condition. The study conducted in undergraduate student in Lagos, Nigeria shows that 11.5%, 51%, and 37.5% had poor, fair, and good knowledge, respectively[13]. These findings are further supported by qualitative insights, which also indicate that the Tharu community generally possesses a low level of awareness about the disease. This highlights a gap in knowledge among community members.

Regarding attitudes and perceptions toward sickle cell disease (SCD), our study found that approximately 73.1% of respondents exhibited a good attitude, while 26.4% had a moderate attitude, and only 0.5% demonstrated a poor attitude. This aligns with the study conducted in students in a Ugandan university where positive attitude towards the SCT is 73.3%, with a mean score of 23.32 ± 5.84 [18]. These findings are supported by qualitative insights, which indicate a positive shift in community attitudes, along with a notable decline in stigma and superstitions. Earlier misconceptions such as associations between SCD and dietary or cultural practices are diminishing.

Regarding preventive practice about sickle cell anemia our study revealed only 22.5% respondents have good preventive practices about sickle cell anemia which is align with the study conducted people living in Yaoundé, Cameroon on which 24.61% respondent done the electrophoresis test [16]. Another study has similar alignment with finding which was carried out in Saudi Adults shows that out of 351 participant only 19.1% had good preventive practice [19]. These finding also suggest although there is good attitude about sickle cell disease there is low level of screening for sickle cell anemia among the Tharu community people. These could be due to the lack of testing service availability and other factors like economic condition.

This study also assessed various socio-demographic, knowledge, attitude about sickle cell Anemia with preventive practice about sickle cell anemia.

Our study shows that participant of age group 33–48 years had more than two times likely to have a preventive practice compare to the age less than 33 years ($aOR = 2.210, p = 0.009, CI = 1.217–4.013$). A similar study was carried out in the Ahafo Region of Ghana revealed that age group 26–35 years had one and half time higher level of preventive practices compare to the lower age group[20]. These findings are further supported by the qualitative findings in this study. The cause of the more preventive practice could be the they are more aware of sickle cell disease

Furthermore, this study showed Bivariate logistic regression analysis of factors associated with Preventive Practices is respondent who have complete secondary education were nearly four times more likely to test sickle cell anemia compared to those with lower level of education ($aOR 3.893, p = 0.003, CI = 1.602–9.46$). This result align with the study carried out in the Lango region, Northern Uganda which has result of Respondents who had completed primary were eight times more likely to test for SCD compared to those with no education ($aOR = 8.2, p = 0.05, 95\%CI = 1.01–66.4$)[21]. This is due to the education enhance knowledge and awareness about sickle cell anemia due to which they are more curious about their hemoglobin genotype

This study shows moderate knowledge is the strongest predictor for preventive practices (aOR = 2.258, $p = 0.004$, CI = 1.305–3.907). This result is align with the study conducted in the western Sudan which has shown the poor knowledge is the strongest predictor for preventive practice (aOR = 3.7, $p = < 0.001$, CI = 1.7–7.9)[22]. This is due to the if people have highier knowledge they perceive severity of disease due to which they compel to screening test.

This study showed that participants living in rural municipalities had three times higher odds of following preventive practices (UOR 3.67, 95% CI: 2.16–6.22) compared to participants from urban municipalities. This may be due to the higher number of screening camps organized by rural municipalities in the Tharu community. These results are also supported by qualitative findings: a key informant interview (KII) from a rural municipality stated that the rural municipality has given more attention to sickle cell anemia prevention and control, and has implemented more programs for this purpose.

Conclusion

This study revealed a relatively favorable attitudes among almost all Tharu people, but only less than half proportion having moderate to good knowledge, and only with just more than one-fifths practicing for sickle cell anemia prevention. It also examined various factors associated with preventive practices for the transmission of sickle cell disease. The study highlights the low level of disease-related knowledge in this high-prevalence ethnic group, which contributes to the ongoing genetic transmission of the condition. Despite having a generally positive attitude toward the disease, most people are unaware of their hemoglobin genotype, which poses a significant challenge to preventing genetic inheritance and controlling the disease. Only one-third of the study participants were aware of their sickle cell status, which represents a major barrier to effective disease control. The study further showed that education level, disease-related knowledge, and the extent of intervention programs such as health education and screening camps are strong predictors for controlling the disease. However, several barriers to preventive practices were identified, including a lack of properly trained health workers, limited availability of testing centers at the peripheral level, inadequate counseling services, poor economic conditions, absence of community-level health interventions, and social stigma associated with sickle cell anemia. SCA Knowledge intervention incorporating attitude among poor urban older adults is recommended.

Abbreviations

AOR

Adjusted odds Ratio

DOHS

Department of Health Service

EDCD

Epidemiological Disease Control Division

FCHV

Female Community Health Volunteer

HH

House Hold

HO

Health Office

IRC

Institutional Review Committee

MOHP

Ministry of Health and Population

NCD

Non-Communicable Disease

NGO

Non-Governmental Organization

NHRC

Nepal Health Research Council

OPD

Out Patient Department

SCA

Sickle Cell Anemia

SCD

Sickle Cell Disease

SCT

Sickle Cell Trait

SHAS

School of Health and Allied Sciences

UOR

Unadjusted odds Ratio

WHO

World Health Organization

Declarations

Ethical approval and consent to participate

This study was carried out in accordance with the ethical principles outlined in the World Medical Association's Declaration of Helsinki for Medical Research Involving Human Subjects.

Research ethics committee

Ethical approval for this study was obtained from the **Ethical Review Board** of the Nepal Health Research Council (NHRC), Government of Nepal (**Reference No. 1536**). Written permission to conduct the study was also obtained from Janaki Rural Municipality, Durgauli, Kailali, and Tikapur Municipality, Kailali.

Informed Consent

Written informed consent was obtained from each participant prior to the interview after providing detailed information about the study objectives and ensuring their understanding of confidentiality. Participant confidentiality was strictly maintained throughout the study. The informed consent form and the questionnaire were translated into the local language to facilitate comprehension. Participants were informed of their right to refuse participation or withdraw their consent at any stage of the study without any consequences.

Risk and benefits

The study was done in such a way that no harmful effects were created for the participants. The participants benefited from the health educational during data collection time, which focused on general counseling about sickle cell anemia

Privacy and confidentiality

Privacy and confidentiality were strictly maintained. All the data was anonymized, and unique codes were given for personal identifiers. Data was securely stored and accessible only to the research team.

Consent for publication

Not Applicable.

Dissemination of Result

The research findings were disseminated at the School of Health and Allied Sciences, Pokhara University, through a presentation and the submission of the final thesis (black book). Similarly, the study findings and recommendations were shared with the local governments of Tikapur Municipality and Janaki Rural Municipality.

Competing interests

All authors involved in this study declare that they have no competing interests.

Formal analysis

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Author Contribution

Birkha Bahadur Bistand Hari Prasad Kaphle conceptualized all the work related to research and wrote the main manuscript text and done entire work related to research Hari Prasad Kaphle gives suggestions for conceptual clarity for the research. Krishna Prasad Sapkota Helps in data collection tool finalization Babita Shrestha Helps in data collection and data entry Abhishek Sapkota helps in the data analysis Yashodha Paudel helps in qualitative data analysis Suma Kunwar helps in Data entry and data collection Damaru Prasad Paneru helps in qualitative data analysis Chiranjivi Adhikari helps in data analysis and finalizing manuscript

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Data Availability

Data will be made available upon the request by the corresponding author.

Supplementary Files

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