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# Knowledge Regarding Sickle Cell Disease among Secondary Level Students of Banke, Nepal

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## ABSTRACT

Sickle cell disease is a hereditary disorder caused by mutations in the HBB gene, and its inheritance pattern has significant implications for family planning. Studying this population provides valuable insight into their awareness of genotype testing, premarital screening, and preventive strategies. Early education and assessment at this stage can contribute to long-term public health interventions aimed at reducing the incidence of sickle cell disease. A descriptive cross-sectional research design was applied to conduct the study. Enumerative sampling technique was applied for the study. The study was conducted among secondary level students of Banke. Data was collected by using self-administered tool. The collected data was analyzed using the Statistical Package for Social Science (SPSS) version 16 through descriptive statics. The study revealed that most (80.5%) of respondents demonstrated inadequate level of knowledge, whereas one fourth (19.5%) of respondents had adequate knowledge regarding sickle cell disease.

*Keywords*: Adolescents, knowledge, secondary-level students, sickle cell disease

## INTRODUCTION

Sickle cell disease is a serious inherited blood disorder. It causes red blood cells to become rigid and sickle-shaped, leading to blockages in blood vessels and health complications (WHO, 2025). The disease is caused by a mutation in the sixth codon of the β-globin gene in hemoglobin (Hb), where glutamic acid is substituted with valine. This change causes the formation of abnormal hemoglobin, leading to chronic hemolytic anemia. As a consequence, red blood cells become rigid and take on a crescent, or sickle, shape (Sankhi et al., 2025).

Sickle cell disease is characterized by episodic acute illness, acute and chronic pain, and progressive multi-organ damage affecting various systems such as bones, spleen, liver, brain, lungs, kidneys, and joints (Joshi et al., 2025). Sickle Cell Disease affects approximately 25 million people worldwide. Each year, about 300,000 babies are born with the condition, with the highest prevalence in sub-Saharan Africa, India, the Mediterranean region, and the Middle East. In Uganda, more than 20,000 babies are born with the disease annually in some high-burden regions, and an estimated 50% to 80% of them die before reaching five years of age (Kanyesigye et al., 2025).

The first HbS gene was identified in 1952 among tribal communities of the Nilgiri Hills in South India by Lehmann and Cutbush. In India, estimated 5–10 million people with the SS type and about 18 million carriers (AS type). Study, show that nearly 50% of all AS and SS newborns worldwide are born in just three countries—Nigeria, the Democratic Republic of the Congo, and India. In India, about 42,016 SS newborns are born each year, accounting for 88% of all homozygous sickle cell cases in Asia (Ganesh et al., 2021).

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In Nepal, Sickle cell disease (SCD) has emerged as a significant yet under-addressed public health challenge, disproportionately affecting the indigenous Tharu community residing in the malaria-endemic Terai region. Although the Tharu population constitutes only 6.6% of Nepal's total population, they account for approximately 58.3% of the country's reported SCD cases (Sankhi et al., 2025).

Despite the identification of the first SCD patient in Nepal in 2003 and the formal recognition of sickle cell disease as a public health problem by the Constituent Assembly in 2014 (Pandey et al., 2017). The most prevalence rate of SCD in Nepal is in Tharu communities and it is estimated that about 30,000 of SCD patient belongs to Tharu communities of mid and far western region of Nepal (Chaudhary and Tharu, 2016).

However, there is limited studies, regarding knowledge and awareness about sickle cell disease among high-prevalence groups such as the Tharu community in Nepal. Limited understanding of its genetic inheritance, symptoms, complications, treatment options, and carrier status contributes to delayed diagnosis, poor disease control, increased complications, and continued transmission across generations. Therefore, assessing the level of knowledge regarding SCD among high-risk populations is essential to identify gaps and generate evidence for targeted health education, improved screening and counseling services aimed to reduce the disease burden and improving quality of life.

## METHODOLOGY

A descriptive cross-sectional research design with a quantitative approach was applied to assess knowledge regarding sickle cell disease among secondary level students. The study was conducted at Shree Saraswati Secondary School, located in Raptisonari Rural-municipality ward no. 3, Banke district of Lumbini province. This school was established in 2035 BS offering educational programs from Nursery to grade 10, 11 and 12. There are 20 teachers and 700 students. The study population was all the students of secondary level studying in 9,10,11 and12 of Shree Saraswati Secondary School Raptisonari Rural-municipality, Banke was the study population. There are 295 students in Grade 9,10,11 and 12. Students who were willing to participate in this study and available at the time of data collection

Table 1 shows that, majority (64.6%) of the respondents were aged less than 16 years. More than half (57.9%) of respondents were female. Most (81.7%) of respondents were Janajati group, half (50.6%) of the respondents were from grade 9. More than half (52.4%) of respondents' from nuclear family. Parental educational status indicated that a substantial proportion of fathers had basic education (44.5%). In contrast, mothers exhibited lower educational attainment, with 59.8% having no formal education. In terms of occupation, more than half of the fathers (54.9%) were engaged in agriculture, similarly, the more than half (54.3%) of mothers were involved in agriculture, few (3.0%) of respondents' from positive family history, almost all (97.0%) of respondents' from negative family history.

**Table 1**

*Respondents' Socio-Demographic Characteristics n=164*

| Variables | Number | Percent (%) |
|---|---|---|
| Age | | |
| <16 | 106 | 64.6 |
| ≥16 | 58 | 35.4 |
| Median (IQR): 16.00 (3) Min 12 Mix 20 | | |
| Sex | | |
| Female | 95 | 57.9 |
| Male | 69 | 42.1 |
| Ethnicity | | |
| Dalit | 9 | 5.5 |
| Janajati | 134 | 81.7 |
| Madhesi | 1 | 0.6 |
| Brahmin/chhetri | 16 | 9.8 |
| Others | 4 | 2.4 |
| Grade | | |
| 9 | 83 | 50.6 |
| 11 | 62 | 37.8 |
| 12 | 19 | 11.6 |
| Types of family | | |
| Nuclear | 86 | 52.4 |
| Joint | 78 | 47.6 |
| Parent's educational status | | |
| Father | | |
| No education | 56 | 34.1 |
| Basic education | 73 | 44.5 |
| Secondary education | 30 | 18.3 |
| More than secondary | 5 | 3.0 |
| Mother | | |
| No education | 98 | 59.8 |
| Basic education | 51 | 31.1 |
| Secondary education | 12 | 7.3 |
| More than secondary | 3 | 1.8 |
| Parent's occupation | | |
| Father | | |
| Agriculture | 90 | 54.9 |
| Business | 61 | 37.2 |
| Service | 6 | 3.7 |
| Other | 7 | 4.3 |
| Mother | | |
| Agriculture | 89 | 54.3 |
| Business | 32 | 19.5 |
| Service | 1 | 0.6 |
| Homemaker | 38 | 23.2 |
| Other | 4 | 2.4 |
| Family history | | |
| Yes | 5 | 3 |
| No | 159 | 97 |

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**Table 2**

*Respondents' Knowledge Regarding Sickle Cell Disease n= (164)*

| Statements | Number | Percent (%) |
|---|---|---|
| **Meaning of sickle cell disease** | | |
| Sickle cell disease is inherited blood disorder | 109 | 66.5 |
| **Characteristics of sickle cell trait*** | | |
| One normal gene and one sickle gene | 72 | 30.6 |
| Usually mild or no symptoms | 57 | 24.3 |
| May pass gene to offspring | 106 | 45.1 |
| **Cause of sickle cell disease** | | |
| Mutation in the hemoglobin gene | 73 | 44.5 |
| **Sickle cell disease mainly affects** | | |
| Red blood cells | 69 | 42.1 |
| **Sickle cell disease is inherited through** | | |
| From both parents carrying the gene | 100 | 61.0 |
| **Common symptoms of sickle cell disease** | | |
| Severe pain episodes | 57 | 34.8 |
| **Sign and symptoms of sickle cell disease*** | | |
| Pain crises | 67 | 22.9 |
| Anemia | 76 | 26.0 |
| Fatigue | 69 | 23.6 |
| Jaundice | 35 | 12.0 |
| Difficulty in breathing | 45 | 15.4 |
| **Sickle cell disease can be diagnosed through** | | |
| Blood test (hemoglobin analysis) | 140 | 85.4 |
| **Early diagnosis is important for *** | | |
| To prevent complications | 71 | 32.3 |
| To begin proper treatment | 77 | 35.0 |
| To promote genetic counseling | 72 | 32.7 |
| **Treatment modalities of sickle cell disease*** | | |
| Iron containing diet | 84 | 29.6 |
| Blood transfusion | 101 | 35.6 |
| Provide medicine which decrease pain | 35 | 12.3 |
| bone marrow transplant | 64 | 22.5 |
| **Preventive measure of sickle cell disease** | | |
| Pre-marital screening | 117 | 71.3 |
| **Reduce the chance of passing the disease to his or her children** | | |
| Marry a person who does not have sickle cell disease or sickle cell trait | 107 | 65.2 |
| **Preventive measures helps to reduce complications*** | | |
| Vaccination | 74 | 32.5 |
| Healthy lifestyle | 72 | 31.6 |
| Genetic counselling | 82 | 36.0 |
| **Complications of sickle cell disease*** | | |
| Pain | 73 | 22.1 |
| Anemia | 80 | 24.2 |
| Infection | 69 | 20.8 |
| Stroke | 26 | 7.9 |
| Gallstone | 29 | 8.8 |
| Organ damage | 54 | 16.3 |
| **Sickle cell disease falls under free government healthcare services** | | |
| Yes | 120 | 73.2 |
| No | 44 | 26.8 |

*Multiple response**

Table 2 shows that majority (66.5%) of the respondents correctly identified sickle cell disease as an inherited blood disorder. Below half (44.5%) respondents recognized mutation in the hemoglobin gene as the cause, similarly below half (42.1%) respondents correctly identified red blood cells as the primarily affected cells. A majority (61%) respondents understood that the disease is inherited from both parents carrying the gene. Below half (45.1%) respondents acknowledged the possibility of passing the gene to offspring, while one third (30.6%) respondents identified the presence of one normal and one sickle gene and one fourth (24.3%) respondents recognized that it often presents with mild or no symptoms. Above one third (34.8%) respondents correctly identified severe pain episodes as a common

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symptom. One fourth (26%) respondents correctly identified anemia is sign and symptoms of sickle cell disease, similarly one fourth (23.6%)fatigue, and pain crises (22.9%), while below one fourth (15.4%) respondents identified difficulty in breathing and jaundice (12%). Most (85.4%) respondents correctly identified blood testing (hemoglobin analysis) as the primary diagnostic method. Awareness of the importance of early diagnosis was above one third (35%) of respondents recognized initiation of treatment, followed by promotion of genetic counseling (32.7%), and prevention of complications (32.3%). Knowledge of treatment options was variable, above one third (35.6%) of respondents identified blood transfusion, followed by iron-rich diet below one third (29.6%) and bone marrow transplantation below one third (22.5%), while below one fourth (12.3%) of respondents mentioned pain-relieving medications. Majority (71.3%) of respondents identified premarital screening as a prevention of sickle cell disease. Majority (65.2%) of respondents recognizing the importance of marrying a partner without the disease or trait. Measures to reduce complications were most commonly identified as genetic counseling above one third (36%), similarly followed by vaccination (32.5%) and maintenance of a healthy lifestyle (31.6%). Awareness of complications was limited, one fourth (24.2%), similarly pain (22.1%), and infection (20.8%) being the most recognized, while below one fourth (16.3%) respondents identified organ damage, fewer (8.8%)gallstones, and (7.9%) stroke. Most (73.2%) of respondents were aware that sickle cell disease is covered under free government health services.

**Table 3**

*Respondents' Source of Information n= (164)*

| Source of information | Number | Percent (%) |
|---|---|---|
| Radio | 42 | 21.1 |
| Television | 20 | 10.1 |
| Health personal | 69 | 34.7 |
| Internet | 25 | 12.6 |
| Books/Newspaper | 12 | 6.0 |
| Friends/Relatives | 31 | 15.6 |

Table 3 shows that above one third respondents learned about sickle cell disease from health professionals (34.7%), followed by radio (21.1%), friends/relatives (15.6%), internet (12.6%), television (10.1%), and books/newspapers (6%).

**Table 4**

*Respondent's Level of Knowledge Regarding Sickle Cell Disease (n=164)*

| Level of knowledge | Number | Percent (%) |
|---|---|---|
| Adequate knowledge(50% and above) | 32 | 19.5 |
| Inadequate knowledge(<50) | 132 | 80.5 |
| Median (IQR): 12.00 (6) | | |

Table 4 shows that most (80.5%) of respondents demonstrated inadequate knowledge, whereas the below one fourth (19.5%) of respondents exhibited adequate knowledge regarding sickle cell disease.

## DISCUSSION

A descriptive cross-sectional study was conducted with an objective to find out the level of knowledge regarding sickle cell disease among secondary level students of Banke. This study was conducted among 164 respondents.

Regarding socio-demographic information, this study showed that cent percent 100% of the respondents were aged between 10 to 20 years. More than half (57.9%) of respondents were female. The most of respondents were belonged to the Janajati group (81.7%), Over half (50.6%) of the respondents were from grade 9. More than half (52.4%) of respondents were from nuclear family. Parental educational status indicated that a substantial proportion of fathers had basic education (44.5%). In contrast, mothers exhibited lower educational attainment, with 59.8% having no formal education. In terms of occupation, more than half of the fathers (54.9%) were engaged in agriculture, similarly, the majority of mothers were involved in agriculture (54.3%), only a small proportion of respondents (3%) reported a positive family history, whereas majority (97%) reported no such history.

The present study reveals that most (80.5%) of respondents demonstrated inadequate knowledge, whereas the below one fourth (19.5%) of respondents exhibited adequate knowledge regarding sickle cell disease. The finding is consistent by the study conducted by (Ahmad, 2023) in Uganda, showed that majority (65%) of respondents were poor knowledge, one third (30%) of respondents were moderate and

few (5%) of respondents were excellent knowledge about sickle cell disease which is comparable with present study of inadequate knowledge (80.5%). Similarly, a study conducted in Uganda revealed 84.68% had poor knowledge (Kanyesigye et al., 2025). Likewise, a study conducted in Ghana, revealed that 62% of respondents had inadequate knowledge, 35.8% had moderate knowledge and 2.3% had adequate knowledge (Brown et al., 2022). Which is comparable with present study of poor knowledge (80.5%). In contrast a study conducted in Bardiya, Nepal revealed that majority (74.5%) of the respondents demonstrated good knowledge regarding sickle cell disease (Sankhi et al., 2025). The difference in findings of this study with previous study might be due to difference in socio-demographic character, sample size, sampling technique and setting.

## CONCLUSION

The findings of the study, reveals that most of the respondents had poor knowledge regarding sickle cell disease. Majority of the respondents had incomplete information regarding sickle cell disease. So that there is need to increase information regarding sickle cell disease through the preferred community channels like community health workers, Female Community Health Volunteer, mother groups, political leaders, school teachers, as well as radio, television source among students to fulfil the gap.

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