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Original Research Article

A cross-sectional study on BMI, anemia, and quality of life in children with sickle cell disease

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ABSTRACT

Background: Sickle cell disease (SCD), particularly the homozygous HbSS pattern, is a chronic hematologic condition that significantly impacts children's growth and overall quality of life. Malnutrition and anemia are frequently observed complications that contribute to increased morbidity in children with SCD.
Methods: A cross-sectional study was conducted at a tertiary healthcare center in Central India. A total of 194 children aged 5 to 12 years, diagnosed with HbSS sickle cell disease, were selected through convenience sampling. Data were collected using a semi-structured interview schedule conducted during the specialized sickle cell OPD held every Tuesday.
Results: In this study involving 194 children with sickle cell disease, 29.9% were underweight, with a higher proportion among females. Normal BMI was observed in 64.9%, while only 5.2% were overweight, and none were obese. Moderate anemia was present in 73.2% and severe anemia in 26.8%, with a mean hemoglobin of 8.43 g/dl. In terms of quality of life (QoL), most children showed excellent emotional (97.4%) and social functioning (100%), while physical (74.2%) and school domains (67%) were relatively lower but still positive.
Conclusions: The study highlights that despite a high prevalence of anemia and undernutrition, children with sickle cell disease demonstrate strong emotional and social quality of life. However, their physical health and academic performance are modestly affected, indicating the need for targeted nutritional and educational interventions to enhance overall well-being.

Keywords: Anemia, BMI, Children, Cross-sectional study HbSS, Quality of life, Sickle cell disease

INTRODUCTION

Sickle cell disease (SCD) is a hereditary hemoglobinopathy that primarily affects individuals of African, Middle Eastern, and Indian ancestry. Globally, it is estimated that over 300,000 infants are born annually with SCD, and this number is projected to increase significantly in the coming decades due to population growth in high-burden countries.[1] The World Health Organization (WHO) recognizes SCD as a global public health issue, particularly in low- and middle-income countries where health systems face challenges in providing comprehensive care.[2] Despite being preventable and manageable, SCD continues to contribute significantly to childhood morbidity and mortality worldwide, especially in under-resourced settings.[3]

India bears a substantial burden of sickle cell disease, particularly among certain tribal and non-tribal populations across states such as Maharashtra, Madhya Pradesh, Chhattisgarh, Odisha, Jharkhand, and Gujarat.[4] The central, western, and parts of southern India form

what is often described as the "sickle cell belt," where prevalence among certain tribal groups can range from 10% to as high as 35%.[5] Recent estimates suggest that India alone contributes to more than 20% of the global SCD burden, with thousands of affected children born every year.[6] The National Health Mission (NHM) has recognized SCD as a priority area and launched screening and early diagnosis programs to mitigate long-term complications.[7]

Central India, particularly the Vidarbha region of Maharashtra, is home to a large tribal population with a high prevalence of the sickle cell gene. Tertiary healthcare centers in this region play a pivotal role in providing diagnostic and therapeutic services to a demographically diverse population affected by SCD. The tertiary healthcare center where this study is conducted serves as a referral unit for several rural and semi-urban areas, making it an ideal setting for examining the clinical and nutritional challenges faced by children with sickle cell disease. Additionally, it hosts a weekly sickle cell clinic that provides continuity of care, comprehensive check-ups, and a platform for data collection under standardized conditions.

The age group of 5 to 12 years was strategically selected for this study due to several clinical and developmental considerations. This stage in life represents a crucial period of physical and cognitive development, during which children are particularly vulnerable to the effects of chronic illnesses such as SCD. School-age children may begin to show overt signs of growth retardation, undernutrition, or stunted development, which may not be as apparent during infancy or early childhood.[8] Furthermore, the school-going age group allows for more accurate assessment of health-related quality of life (HRQoL), as children become more aware of their health status, school performance, and social relationships.[9] This age group also represents a window of opportunity for timely intervention to optimize growth and development before adolescence.

Body mass index (BMI) is a widely used anthropometric indicator for assessing nutritional status in children. In children with SCD, chronic anemia, increased metabolic demand, recurrent infections, and poor appetite contribute to undernutrition and growth retardation. Several studies have reported a significantly lower BMI-for-age Z-score in children with SCD compared to their healthy counterparts.[10] Malnutrition, particularly undernutrition, can exacerbate the clinical course of SCD, resulting in frequent vaso-occlusive crises, reduced immunity, and impaired school performance. Despite the known association between SCD and growth impairment, limited data exist on the BMI profiles of Indian children with SCD, particularly in rural and tribal settings.

Anemia, a hallmark of sickle cell disease, is caused by chronic hemolysis due to the structural abnormality of sickled hemoglobin. Persistent anemia in children with SCD contributes to fatigue, delayed growth, poor cognitive function, and impaired quality of life.[11] Moreover, anemia is often compounded by nutritional deficiencies such as iron, folate, and vitamin B12, which are prevalent in socioeconomically disadvantaged populations. Understanding the degree and clinical consequences of anemia in this age group can help tailor nutritional and pharmacological interventions in this vulnerable population.

Quality of life is increasingly recognized as a critical parameter in the management of chronic pediatric illnesses. In children with SCD, recurrent pain episodes, school absenteeism, psychosocial stress, and fatigue significantly impair their quality of life. Studies across different regions of the world have highlighted lower scores in physical, emotional, and social well-being domains among children with SCD compared to healthy peers[12]. However, there remains a scarcity of region-specific data from India on how SCD impacts quality of life, particularly from the child's and caregiver's perspectives. Cultural, socioeconomic, and healthcare access factors all influence how the disease is experienced and managed, and thus, impact overall quality of life.

This study seeks to fill the existing gaps in literature by exploring the intersection of three important aspects BMI, anemia, and quality of life in children aged 5 to 12 years living with sickle cell disease in Central India. By conducting this research at a tertiary healthcare center, we aim to leverage clinical expertise, diagnostic infrastructure, and an established patient registry to obtain reliable and comprehensive data. The findings of this study have the potential to inform policy and clinical practice by identifying the most pressing nutritional and psychosocial needs of pediatric SCD patients in this region.

Furthermore, by focusing on a well-defined and under-studied subgroup, this study contributes to a growing body of evidence advocating for holistic management of SCD beyond pharmacologic interventions. Addressing malnutrition and improving quality of life should be integral components of care strategies. With India emerging as a significant contributor to the global burden of SCD, region-specific studies are essential for contextualizing interventions that are culturally and socially appropriate. This research not only underscores the importance of a multidisciplinary approach to managing chronic illnesses like SCD but also aims to enhance pediatric health outcomes in some of the most underserved communities of the country.

METHODS

Study design

A cross-sectional study was conducted at a tertiary healthcare centre in central India. A total of 194 children,

aged 5 to 12 years and diagnosed with SCD (HbSS type confirmed through Hb electrophoresis), were enrolled using a convenience sampling method. Data were collected through face-to-face interviews using a semi-structured questionnaire.

Study population

Children aged 5 to 12 years diagnosed with homozygous sickle cell disease (HbSS pattern).

Sample size and sampling technique

A total of 194 children were included using a convenient sampling technique.

Study duration

This study was conducted from September 2024 to March 2025.

Inclusion criteria

Children in the age group of 5 to 12 years, diagnosed with sickle cell disease as homozygous (HbSS) by Hb electrophoresis. Children who are accompanied by their mother or father to sickle cell OPD.

Exclusion criteria

Children who are diagnosed as sickle cell trait (HbAS), other hemoglobinopathies of sickle cell disease (e.g., HbSO, HbSE, HbSD, HbAS, HbS thalassemia), parents or child who refused to give consent/ assent for the study were excluded.

Data collection method

The data for this study were collected from children aged 5 to 12 years diagnosed with sickle cell disease (HbSS pattern) attending the sickle cell outpatient department.

The data collection was conducted at the pediatric clinic, where a dedicated sickle cell OPD is held every Tuesday. On average, 12 to 15 children with sickle cell disease visited the OPD each week, out of these, about 8 to 10 children who met the inclusion criteria were selected for the study using a convenience sampling method.

Data collection continued weekly until the required sample size was achieved. Informed and written consent from parent and assent from child was obtained in their vernacular language after explaining them the nature and the purpose of study. Data was collected in a pre-designed, pre-tested, questionaire by face to face interview. Quality of life of sickle cell children was assessed by pedsQL 4.0 Generic core scale. Anthropometric measurements like height, weight of the study subjects was taken. Haemoglobin was estimated by digital haemoglobinometer.

Data management and analysis

Data were entered into Microsoft Excel and analyzed using SPSS software. Continuous variables were summarized as mean with standard deviation. Categorial variables were summarized as proportions.

RESULTS

The present study included a total of 194 children diagnosed with sickle cell disease, comprising 105 males and 89 females. The nutritional status of these children was assessed using the Indian Academy of Pediatrics (IAP) 2015 BMI growth chart for the 5-18-year age group. A notable proportion of the study population was found to be undernourished, with 26.6% of males and 33.8% of females falling below the 3rd BMI percentile, categorizing them as underweight. This indicates a relatively higher prevalence of undernutrition among female participants as compared to males. On the other hand, the majority of children had a BMI within the normal range (3rd to 90th percentile), with 67.6% of males and 61.8% of females demonstrating normal BMI values. Overweight status (90th to 97th percentile) was observed in a small fraction of participants-5.8% of males and 4.4% of females while no child from either gender fell in the obese category (>97th percentile). Overall, out of the 194 children, 29.9% were underweight, 64.9% had normal weight, and only 5.2% were overweight, reflecting a predominant trend of normal BMI distribution but with a significant burden of undernutrition.

Table 1: Body mass index of study subjects.

Body mass index percentile	Male	Percentage (%)	Female	Percentage (%)	Total, N (%)
Less than 3rd percentile (underweight)	28	26.6	30	33.8	58 (29.9)
3rd to 90th percentile (normal)	71	67.6	55	61.8	126 (64.9)
90th to 97th percentile (overweight)	6	5.8	4	4.4	10 (5.2)
Above 97th percentile (obese)	0	0	0	0	0
Total	105	100	89	100	194 (100)

When evaluating the anemia status, no child in the study group was found to have mild anemia (Hb 11-11.4 g/dL), indicating that anemia in this cohort was of more concerning severity. A substantial 73.2% of the children

were diagnosed with moderate anemia (Hb 8-10.9 g/dl), while 26.8% exhibited severe anemia (Hb <8 g/dl). The mean hemoglobin concentration was 8.43±1.23 g/dl, with a range from 6.8 to 10.4 g/dl, suggesting that anemia is a prominent and clinically relevant issue among children with sickle cell disease in this population.

Table 2: Anemia status in children with sickle cell disease.

Anemia status	Number	Percentage (%)
Mild anemia (11-11.4 g/dl)	0	0
Moderate anemia (8-10.9 g/dl)	142	73.2
Severe anemia (< 8g/dl)	52	26.8
Total	194	100

In terms of quality of life, measured using the Pediatric Quality of Life Inventory (PedsQL) scale, the highest scores were observed in the social domain, where 100% of the children scored above 75%, indicating excellent social functioning. Similarly, the emotional domain reflected a strong outcome, with 97.4% of children scoring in the excellent category and only a small percentage (2.6%) falling in the good range. The physical domain, however, revealed more variability, with 74.2% scoring excellent, while 20.6% had good scores and 5.1% fell into the fair category. The school domain showed comparatively lower performance, with 67% of children having excellent scores, 27.8% with good scores, and 5.1% with fair scores, indicating possible challenges in academic engagement or school-related functioning due to their health status. Overall, when total PedsQL scores were considered, 83.5% of children reported an excellent quality of life, while 16.5% fell into the good category. Notably, none of the children fell in the poor or fair categories in the total QoL assessment, reflecting an overall positive perception of life quality among most of the participants.

Table 3: Quality of life scores in children with sickle cell disease (PedsQL scale).

Peds ql Domain score	Physical domain number	%	Emotional domain number	%	Social domain number	%	School domain number	%	Overall number	%
>75% (Excellent)	144	74.22	189	97.42	194	100	130	67.03	162	83.51
50-75% (Good)	40	20.64	5	2.58	0	0	54	27.83	32	16.49
25-49% (Fair)	10	5.14	0	0	0	0	10	5.14	0	0
<25% (Poor)	0	0	0	0	0	0	0	0	0	0
Total	194	100	194	100	194	100	194	100	194	100

%=Percentage

DISCUSSION

In the present study of 194 children with sickle cell disease (SCD), a considerable proportion 29.9% were underweight, with undernutrition more pronounced among females (33.8%) than males (26.6%). This finding aligns closely with the observations of Ukah et al in Nigeria, who reported underweight prevalence between 30-40% in SCD children, although they identified a slightly higher male preponderance.[25] The trend is similarly reflected in a rural Indian cohort described by Rao et al, where 28% of children were underweight, reinforcing the persistence of malnutrition in low-resource settings.[26] Conversely, research from developed countries, including Chawla et al in the U.S. and Jones et al in the UK, documented much lower underweight rates (~5-10%), but significantly elevated overweight/obesity rates (~20-36%)-a stark contrast to our cohort's overweight prevalence of just 5.2%.[27,28] Notably, Smith et al in the Netherlands found approximately 16% of children with SCD were overweight or obese.[29] These disparities likely reflect socioeconomic and healthcare delivery differences, dietary practices, and disease management strategies across regions.

Our finding of normal BMI in 64.9% of participants (67.6% males, 61.8% females) echoes the work of Thomas et al (2015) in Brazil, who documented normal weight in ~60% of SCD children using similar age-adjusted growth charts.[30] Zemel et al also reported comparable normal-weight prevalence (~65%) across a multinational cohort, further validating our results.[31] However, in contrast, an Egyptian study by El-Gendy et al observed only 50% of children maintaining normal BMI, possibly reflecting differences in nutritional access and public health infrastructure.[32]

From a hematologic perspective, all children in our study exhibited moderate to severe anemia with 73.2% in the moderate range and 26.8% in the severe range consistent with prior investigations. Ballas et al and Kearney et al reported similar hemoglobin distributions (65-75% moderate anemia, 20–30% severe).[20] Ahmed et al in Sudan observed analogous findings, establishing the

universal burden of anemia in pediatric SCD across varied epidemiological contexts.[25]

Quality-of-life (QoL) assessment via the PedsQL instrument in our cohort yielded surprisingly robust scores: emotional and social domains were particularly strong, with 97.4% and 100% of participants scoring in the excellent category, respectively, and overall QoL was excellent in 83.5% of children. This is markedly better than the results of Panepinto et al in the U.S. and Palermo et al in Portugal, where only ~50-60% of children achieved comparable overall QoL scores.[24,22] However, Panepinto's work revealed domain-specific strengths similar to ours-social and emotional well-being typically scored higher than physical functioning-underscoring a consistent pattern across cultural settings.

In contrast, a meta-analysis by Stokoe et al demonstrated notably reduced QoL among SCD patients compared to healthy controls (effect size -0.93), with physical and school domains disproportionately affected.[33] Our data exhibit lower school-domain scores (67% excellent) relative to emotional and social domains, which mirrors Stokoe's conclusions but at quantitatively higher levels, perhaps attributable to superior support systems or less severe disease trajectories in our population.

Furthermore, Vuong et al reported that pain frequency and severity are inversely correlated with school functioning, a pattern likely present in our cohort given the modest school-domain performance.[34] This suggests that recurrent vaso-occlusive events, although not explicitly measured here, may impair academic engagement.

Longitudinal data from Chawla's group and Miniño et al further indicate that interventions such as hydroxyurea and chronic transfusions which elevate hemoglobin are linked to improved BMI and QoL outcomes.[35] Our concurrent findings observing low overweight prevalence amidst moderate anemia-underscore the importance of hemoglobin optimization in nutritional and psychosocial rehabilitation. These associations are supported by Chawla et al who identified hemoglobin as a predictor of BMI in their U.S.-based cohort.[27]

Cultural and gender-specific dynamics may also shape QoL. Stokoe et al both reported worse QoL among female participants, yet in our female cohort despite higher undernutrition overall QoL remained high, suggesting possible resilience or supportive family structures that buffer against gender-based disparities.[36] Alternatively, differences in health education or community integration might compensate for nutritional disadvantages in females.

Academic functioning, while lower than other domains, nonetheless outperformed several international cohorts. For instance, Palermo et al and Thomas et al reported school-domain scores for SCD children around 50%, significantly trailing our 67% performance.[22,37] This may reflect differential access to educational support, flexible schooling policies, or ease of academic adaptation in our subject environment.

This study has few limitations. As a cross-sectional study, the research provides a snapshot of the BMI, anemia status, and quality of life at a single point in time. This limits the ability to establish causal relationships between the variables studied. The use of convenience sampling may introduce selection bias. Children who attended the tertiary healthcare center on clinic days may not be representative of the broader population of children with sickle cell disease, particularly those in remote or underserved areas. Since the study was conducted at a single tertiary healthcare center in Central India, the findings may not be generalizable to other regions with different sociodemographic or cultural characteristics. Additionally, the study relied on parent -reported data, this introduces the possibility of recall bias and social desirability bias, may not accurately reflects the child's experiences. The study may not have captured all factors influencing nutritional status and anemia, such as dietary intake, socioeconomic status, micronutrient deficiencies (iron, folate, B12), or parasite infections. The 5-12 age group includes a wide developmental range, and the physical and psychosocial differences within this range may affect the interpretation of quality of life and nutritional indicators.

CONCLUSION

The present study highlights significant nutritional and hematological challenges along with the quality of life among children aged 5 to 12 years diagnosed with sickle cell disease (Hbss). Nearly one-third of the participants were found to be underweight based on the Indian Academy of Pediatrics (IAP) 2015 BMI-for-age growth standards, with undernutrition being slightly more prevalent among females than males. Only about two-thirds had normal weight, and almost none were overweight or obese. Anemia status of children all children in the study were anemic, with a large majority having moderate anemia, and about one-fourth suffering from severe anemia. No child had mild or normal hemoglobin levels, highlighting a major burden of anemia in this population. In the physical domain, about three-fourths of children had excellent quality of life, while the rest showed varying degrees of difficulty. The emotional and social domains were generally well-maintained, with almost all children scoring in the excellent range, suggesting strong emotional and social support. However, in the school domain, only about two-thirds had excellent scores, with the rest showing moderate or fair performance, possibly due to health-related absenteeism or learning challenges. Overall, a large majority of children had excellent total quality of life scores, but a significant minority had lower scores, mostly influenced by poor physical health and school functioning.

Recommendations

In light of the findings improving nutrition by initiating tailored nutrition programs with calorie-dense, iron-rich foods and micronutrient supplementation to address undernutrition. Managing anemia effectively by ensuring routine hemoglobin testing and provide appropriate iron, folic acid, or other supplements. Addressing contributing factors such as chronic infections, hemolysis, and poor diet. Offering academic support and flexibility in school attendance for children with frequent hospital visits. Collaborating with schools for individualized learning plans and regular monitoring. Continue psychosocial interventions by encouraging emotional counseling, peer interaction, and community-based support to maintain the already good emotional and social functioning. Strengthening Health Services: by Building integrated sickle cell clinics with pediatric, nutrition, and counseling services under one roof. Using tools like PedsQL for regular assessment and individualized follow-up.

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