I. Introduction

Sickle Cell Disease (SCD) is a hereditary haemoglobin disorder characterized by chronic anemia, recurrent pain crises, and multi-organ complications, which can profoundly affect daily functioning and well-being. Adolescents with SCD face physical, emotional, social, and academic challenges that can significantly reduce health-related quality of life (HRQoL).[1 2] Global evidence shows that children and adolescents with SCD report lower HRQoL than healthy peers, particularly in physical functioning, pain, general health, and emotional domains. [3 4] Factors such as disease severity, frequency of crises, psychosocial support, and socioeconomic status influence HRQoL outcomes. [4 5] Despite the burden of SCD in Nepal, data on adolescent HRQoL are limited. Assessing QoL in this population is critical for identifying the most affected domains, informing interventions, and guiding patient-centered care tailored to adolescents with SCD in Nepal.

METHODS

1. Study Design

This was a descriptive cross-sectional study

2. Place and duration of study

The study was conducted in Belauri (Kanchanpur) and Hasuliya, Joshipur, and Urma (Kailali), Nepal. Data collection will take place during health camps organized by Seti Provincial Hospital at different time frames as scheduled by the hospital. These camps provide an accessible platform to reach adolescents with Sickle Cell Disease from multiple communities, facilitating efficient recruitment and data collection.

3. Ethical approval

Ethical approval was obtained from the Institutional Review Board of the Nepal Health Research Council (Reg. no. 83-2022 P). Administrative approval was also secured from the local municipality to access facility records.

4. Inclusion and Exclusion criteria

The study was include adolescents aged 10–19 years with a confirmed diagnosis of Sickle Cell Disease who are residents of the study sites, namely Belauri (Kanchanpur) and Hasuliya, Joshipur, and Urma (Kailali). Participants must be clinically stable at the time of data collection, able to understand and respond to the questionnaire, and have provided written informed consent from their parents or guardians along with their own assent. Adolescents will be excluded if they have other chronic illnesses that could independently affect quality of life, are currently experiencing an acute sickle cell crisis or hospitalization, are unable to communicate or comprehend the questionnaire due to cognitive or language barriers, or if they or their guardians refuse to provide consent or assent.

5. Sample size and sampling

The study was use total enumeration. All eligible adolescents with Sickle Cell Disease attending the health camps organized by Seti Provincial Hospital in Belauri (Kanchanpur) and Hasuliya, Joshipur, and Urma (Kailali) will be invited to participate

6. Statistical analysis and software used

Data will be entered and analyzed using SPSS version 29. Descriptive statistics, including frequencies, percentages, means, and standard deviations, will be used to summarize demographic, clinical, and quality of life variables. Comparative analyses such as t-tests or ANOVA will be used to examine differences in quality of life scores across groups (e.g., age, sex). Associations between quality of life and clinical or sociodemographic factors will be assessed using inferential statistics. A p-value < 0.05 will be considered statistically significant. Data will be presented in tables to provide a clear overview of the findings.

RESULTS

A total of 180 adolescents living with Sickle Cell Disease participated in the study and almost evenly distributed by sex, with 51.1% males and 48.9% females. Regarding age, 47.8% were 10–15 years old, while 52.2% were 16–19 years old. The majority of participants belonged to the Janjati ethnic group (99.4%), with only a small proportion from the Madhesi group (0.6%).

Most adolescents had received formal education (96.1%), while a few were able to read and write (1.7%) or had informal education (2.2%). Family type was almost equally distributed, with 46.7% living in nuclear families and 53.3% in joint families.

Only 5.6% reported having other chronic diseases, and similar proportions reported alcohol use (5.6%) or smoking (3.3%). Most participants were adherent to medication (78.3%) and attended timely follow-up visits (72.2%), indicating good continuity of care among the majority of adolescents with SCD.

The quality of life of adolescents in Nepal, as measured by the SF-36, showed differences across age groups in multiple domains. For the younger group (10–15 years), median scores were higher than the older group (16–19 years) in most domains, indicating better perceived health. Specifically, younger adolescents reported higher median scores in Health Change (75 vs. 75), Physical Functioning (80 vs. 70), Role Physical (100 vs. 75), Role Emotional (100 vs. 66.7), Social Functioning (81.25 vs. 62.5), Bodily Pain (67.5 vs. 57.5), Mental Health (65.71 vs. 54.29), and the Mental Component Summary (92.28 vs. 77.89).

Statistically significant differences were observed in Social Functioning ($p = 0.020$), Bodily Pain ($p = 0.003$), Mental Health ($p = 0.002$), Vitality ($p = 0.021$), and the Mental Component Summary ($p = 0.003$), while Physical Component Summary and other domains showed no significant differences.

In parametric domains such as Vitality and Physical Component Summary, younger adolescents also had slightly higher mean scores than older adolescents. Overall, the findings

suggest that younger adolescents in Nepal report better quality of life and mental well-being than older adolescents, particularly in social, pain, and mental health domains.

Discussion

This study aimed to assess the quality of life (QoL) of adolescents living with Sickle Cell Disease (SCD) in Nepal, using the SF-36 scale to measure multiple domains of health. The findings suggest that younger adolescents (10–15 years) report a better overall quality of life compared to older adolescents (16–19 years), particularly in domains related to mental health, bodily pain, and social functioning. These results align with previous studies, where younger patients with chronic illnesses often report better perceived health, possibly due to fewer disease complications or a greater capacity for resilience. For instance, a study found that younger patients with chronic illnesses tend to report better overall health perceptions compared to older individuals who face the psychological burden of transitioning into adulthood while managing a chronic condition. [6]

The observed differences between age groups may reflect the challenges of transitioning from childhood to adolescence, a developmental period often marked by increased psychological and social challenges. Adolescence is characterized by identity formation, peer pressure, and an increased awareness of disease limitations. [7] This transition period is crucial in determining how adolescents cope with SCD—highlighted that older adolescents with chronic conditions, including SCD, often experience heightened psychological distress, which may contribute to poorer QoL scores. [1]

One of the key findings of this study was that younger adolescents reported significantly better scores in mental health ($p = 0.002$), bodily pain ($p = 0.003$), and social functioning ($p = 0.020$), as well as higher vitality scores ($p = 0.021$). These results suggest that younger adolescents in Nepal may experience less pain and better emotional well-being, potentially due to stronger family support and greater social integration. In contrast, older adolescents reported significantly lower scores in these domains. This is consistent with findings from[8], which demonstrated that older adolescents with SCD often report worse psychosocial

outcomes due to the complex interaction between chronic illness and the demands of adolescence.[3]

The lack of significant differences in domains such as physical functioning and role emotional between the two age groups could be attributed to the relatively stable nature of these dimensions in adolescents with SCD. [9] discussed how physical functioning in adolescents with chronic illnesses often stabilizes after initial challenges, suggesting that SCD may not drastically change physical health over time. [7] Similarly, role emotional may be influenced by broader psychosocial factors beyond disease status, such as family dynamics and coping mechanisms, rather than disease severity alone.

Additionally, the study revealed a high level of medication adherence (78.3%) and timely follow-up (72.2%) among the participants, which suggests that adolescents with SCD in Nepal generally have good continuity of care. However, 5.6% of the sample reported alcohol use, and 3.3% reported smoking, highlighting the need for targeted interventions to improve lifestyle behaviors among this vulnerable population. [5] noted that risky behaviors like smoking and alcohol use are often higher in adolescents with chronic illnesses, and this warrants specific attention in health interventions.

The finding that younger adolescents scored higher in most QoL domains may reflect a more favorable experience of living with SCD, possibly due to greater family support and fewer disease-related complications. [10]. [11] found that adolescents in the earlier stages of disease management generally report better health outcomes, likely because they have fewer years of experience dealing with the disease's complications. However, the challenges faced by older adolescents, particularly in mental health and social domains, emphasize the need for age-appropriate support systems that can address the emotional and psychological needs of adolescents with chronic illnesses like SCD. [8]

Implications for Practice and Future Research

These findings have important implications for healthcare providers and policymakers in Nepal. There is a need for comprehensive, age-specific interventions that not only address

the physical aspects of managing SCD but also focus on the psychological and social well-being of adolescents. As adolescents with SCD approach adulthood, they may face unique challenges related to their disease, which can affect their quality of life. Psychosocial support, counseling, and education about disease management are crucial, particularly for the older age group, who may be at greater risk for mental health issues. Discussed how age-specific interventions can be tailored to meet the psychological needs of adolescents as they transition into adulthood. [12]

Future research should focus on longitudinal studies to explore the long-term changes in quality of life as adolescents transition into adulthood, as well as the factors that influence this transition. Studies that incorporate a more diverse ethnic sample and explore additional variables such as socioeconomic status, family support, and disease severity would provide a more comprehensive understanding of the factors that influence QoL in adolescents with SCD in Nepal. Longitudinal studies to better understand how QoL evolves over the course of adolescence and into adulthood for those with chronic diseases like. [10]

Conclusion

This study highlights that adolescents living with Sickle Cell Disease in Nepal experience varying levels of quality of life across age groups. Younger adolescents (10–15 years) generally reported better physical, social, and mental well-being compared to older adolescents (16–19 years). Social functioning, bodily pain, mental health, vitality, and overall mental health summary scores were significantly lower in older adolescents, indicating that age-related factors may influence their perceived quality of life. These findings emphasize the need for age-specific interventions and psychosocial support to improve the overall well-being of adolescents with SCD, particularly as they transition into older adolescence.

Limitation

Being cross-sectional, it captures quality of life at a single point in time and cannot establish causal relationships or changes over time. The majority of participants belonged to the Janjati ethnic group, which may limit the generalizability of the findings to other ethnic populations

in Nepal. Quality of life was assessed using self-reported questionnaires, which could be influenced by recall bias or social desirability. Additionally, detailed clinical information, such as the frequency of pain crises or disease severity, was not comprehensively analyzed, which may affect the observed outcomes. Other factors, including family support, socioeconomic status, and access to healthcare, could also have influenced quality of life but were not fully controlled for in this study.