International Journal of Research in Medical Sciences
Nadgir A et al. Int J Res Med Sci. 2026 Mar;14(3):1046-1050
www.msjonline.org
pISSN 2320-6071 | eISSN 2320-6012
DOI: https://dx.doi.org/10.18203/2320-6012.ijrms20260624

Original Research Article

Health-related quality of life in children aged 8-12 years with thalassemia: a cross-sectional study using the pediatric quality of life inventory PedsQL

Akshata Nadgir[1]*, Pallavi Wajapey[2], Y. Sai Sudha Samaja[1], Ramya S. K.[3]

[1]Department of Community Health Physiotherapy, RV College of Physiotherapy, Bengaluru, Karnataka, India
[2]Department of Pediatric Physiotherapy, RV College of Physiotherapy, Bengaluru, Karnataka, India
[3]Intern, RV College of Physiotherapy, Bengaluru, Karnataka, India

Received: 29 December 2025
Revised: 03 February 2026
Accepted: 05 February 2026

***Correspondence:**
Dr. Akshata Nadgir,
E-mail: akshu289@gmail.com

ABSTRACT

Background: Thalassemia is a chronic hereditary hemoglobinopathy characterized by defective hemoglobin synthesis, resulting in lifelong anaemia and dependence on regular blood transfusions and iron chelation therapy. The prolonged treatment burden, frequent hospital visits, and associated physical and psychosocial challenges can significantly impair the quality of life (QoL) of affected children. Assessment of QoL is essential to understand the multidimensional impact of the disease beyond clinical parameters and to support holistic, patient-centred care.
Methods: A cross-sectional study was conducted among 40 children aged 8-12 years diagnosed with thalassemia and attending Samraksha- Thalassemia Day Care Centre, Bengaluru. Quality of life was assessed using the parent-proxy version of the pediatric quality of life inventory (PedsQL) 4.0 generic core scales, which evaluates physical, emotional, social, and school functioning. Demographic and anthropometric data were recorded. Descriptive statistics were used, and associations between overall QoL scores and gender, age, height, weight, and body mass index were analysed using appropriate statistical tests.
Results: Quality of life was compromised across all domains. The lowest median scores were observed in physical functioning (median: 3; IQR: 2-5) and social functioning (median: 3; IQR: 1-4). The median overall QoL score was 14.5 (IQR: 11-20.25). Male children demonstrated significantly higher overall QoL scores compared to female children (p=0.024).
Conclusions: Children with thalassemia experience significant impairments in multiple domains of quality of life, emphasizing the need for comprehensive multidisciplinary management.

Keywords: Children, Cross-sectional study, Pediatric quality of life inventory, Physiotherapy, Quality of life, Thalassemia

INTRODUCTION

Thalassemia is the most prevalent inherited hemoglobinopathy worldwide and represents a significant public health concern, particularly in low- and middle-income countries. It is characterized by reduced or absent synthesis of α- or β-globin chains, resulting in defective haemoglobin formation, ineffective erythropoiesis, and chronic anaemia. Based on the affected globin chain, thalassemia is classified into alpha and beta types, with beta-thalassemia major being the most severe form requiring lifelong medical management.[1]

India bears a disproportionate burden of thalassemia, with an estimated carrier rate of 3-4% nationally and up to 17% in certain regions. Approximately 10,000-15,000 children

with transfusion-dependent thalassemia are born annually, placing a substantial strain on healthcare systems and families.[2,3] The chronic nature of the disease significantly affects not only survival but also physical function, participation in daily activities, and overall quality of life.

Management of transfusion-dependent thalassemia primarily involves regular packed red blood cell transfusions every three to four weeks to maintain pre-transfusion haemoglobin levels between 9 and 10.5 gm/dl, along with iron chelation therapy to prevent iron overload. Despite advances in medical care, repeated transfusions lead to iron deposition in vital organs, causing cardiomyopathy, hepatic dysfunction, endocrine abnormalities, delayed growth, and skeletal deformitie.[4-6] These complications have direct implications for physical performance, exercise tolerance, and musculoskeletal health in affected children.

From a physiotherapy perspective, children with thalassemia are at increased risk of reduced aerobic capacity, muscle weakness, postural deviations, delayed motor development, and decreased participation in physical and recreational activities. Chronic anemia and repeated illness-related inactivity contribute to early fatigue, reduced endurance, and functional limitations, which may negatively impact school attendance, play behavior, and social interaction. Physiotherapy plays a vital role in addressing these impairments through exercise prescription, posture correction, functional training, and activity modification aimed at enhancing physical capacity and participation.[5,6]

In addition to physical impairments, children with thalassemia often experience psychosocial challenges, including poor self-esteem, anxiety, depressive symptoms, and social isolation due to chronic illness and visible physical differences. Frequent hospital visits and fatigue further interfere with academic performance and peer relationships. These factors collectively impair health-related quality of life (HRQoL). Previous studies using validated tools such as the pediatric quality of life inventory (PedsQL) have consistently demonstrated significantly lower scores across physical, emotional, social, and school functioning domains in children with thalassemia compared to healthy peers.[7-9]

Assessment of quality of life is therefore essential in pediatric thalassemia, as it captures the multidimensional impact of the disease beyond clinical parameters such as haemoglobin levels. For physiotherapists, QoL assessment aligns with the international classification of functioning, disability and health (ICF) framework by identifying impairments, activity limitations, and participation restrictions. Understanding these domains facilitates individualized rehabilitation planning and multidisciplinary intervention.

Hence, the present cross-sectional study was undertaken to evaluate the quality of life among children aged 8-12 years with thalassemia using the parent-proxy version of the pediatric quality of life inventory (PedsQL) 4.0 generic core scales.

METHODS

A cross-sectional observational study was conducted at Samraksha- Thalassemia Day Care Centre, Gavipuram, Bengaluru. A total sample size of 40 children aged between 8 and 12 years with a confirmed diagnosis of thalassemia were recruited using a purposive sampling technique.

Children who were clinically stable at the time of assessment and whose parents or caregivers provided written informed consent were included in the study. Children outside the specified age range, those with severe cognitive impairment or major psychiatric illness, and those with severe comorbid medical conditions were excluded to ensure reliable assessment of quality of life.

Quality of life was evaluated using the pediatric quality of life inventory (PedsQL) version 4.0 generic core scales, parent-proxy report for children aged 8-12 years. The PedsQL 4.0 is a validated and reliable generic instrument designed to assess health-related quality of life in pediatric populations. It consists of 23 items grouped into four domains: physical functioning (8 items), emotional functioning (5 items), social functioning (5 items), and school functioning (5 items). The questionnaire has been extensively used in both healthy children and those with acute and chronic conditions to assess functional health, activity limitations, participation, and overall well-being.

Prior to data collection, permission to conduct the study was obtained from the authorities of Samraksha-Thalassemia Day Care Centre. Parents or caregivers were informed about the objectives and procedures of the study, following which written informed consent was obtained. Demographic information, including age and gender, along with anthropometric measurements such as height and body weight, were recorded using a structured Google form. Height was measured using a stadiometer, and body weight was measured using a calibrated weighing machine under standardized conditions.

Statistical analysis

Statistical analysis was performed using the Statistical Package for the Social Sciences (SPSS). Descriptive statistics were used to summarize demographic, anthropometric, and quality of life data. Continuous variables were expressed as mean±standard deviation or median with interquartile range, as appropriate. The association between overall quality of life scores and gender was analysed using an independent t-test. The relationship between overall quality of life scores and age, height, weight, and body mass index was assessed using Pearson's correlation coefficient. A p value of less than 0.05 was considered statistically significant.

RESULTS

A total of 40 children with thalassemia aged between 8 and 12 years were included in the study. The mean age of the participants was 10.15±1.51 years. The mean height was 117.83±12.00 cm, mean body weight was 23.58±4.60 kg, and mean body mass index was 17.08±3.01 kg/m^2. Among the participants, 21 (52.5%) were male and 19 (47.5%) were female. The demographic and anthropometric characteristics of the study population are presented in Table 1.

Table 1: Demographic and anthropometric characteristics of the study population.

Variables	Mean±SD/N (%)	Range
Age (years)	10.15±1.51	8-12
Height (cm)	117.83±12.00	96-149
Weight (kg)	23.58±4.60	16-38.9
BMI (kg/m²)	17.08±3.01	11.88-23.64
Gender- Male	21 (52.5)	—
Gender- Female	19 (47.5)	—

Table 2: Domain-wise quality of life scores (PedsQL 4.0).

Domain	Range	Mean±SD	Median (IQR)
Physical functioning	0-18	3.88±3.89	3 (2-5)
Emotional functioning	0-11	4.85±2.82	4 (3-7.25)
Social functioning	0-12	2.92±2.41	3 (1-4)
School functioning	0-14	4.70±3.28	4 (3.5-5.25)
Total QoL score	0-46	16.35±8.89	14.5 (11-20.25)

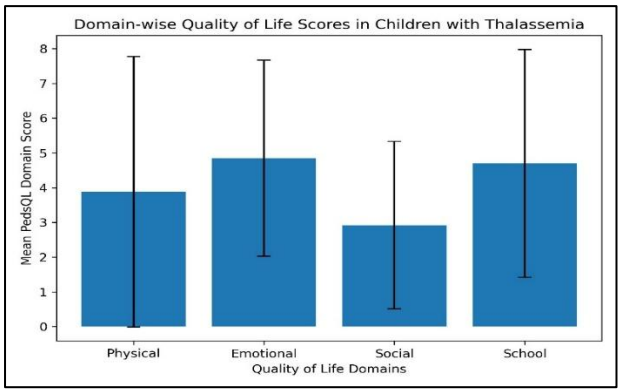

Figure 1: Domain-wise quality of life scores in children with thalassemia.

Quality of life scores assessed using the PedsQL 4.0 varied across different domains. Physical functioning scores ranged from 0 to 18, with a median score of 3 (IQR: 2-5). Emotional functioning scores ranged from 0 to 11, with a median of 4 (IQR: 3-7.25). Social functioning scores ranged from 0 to 12, with a median of 3 (IQR: 1-4), while school functioning scores ranged from 0 to 14, with a median of 4 (IQR: 3.5-5.25). The overall quality of life scores ranged from 0 to 46, with a median score of 14.5 (IQR: 11-20.25). Domain-wise quality of life scores are summarized in Table 2 and Figure 1.

Table 3: Association between quality of life and gender.

Gender	N	Mean±SD	Median (IQR)	P value
Female	19	13.05±7.40	12 (8.5-15.5)	
Male	21	19.33±9.22	19 (14-23)	0.024*

*Statistically significant at p<0.05

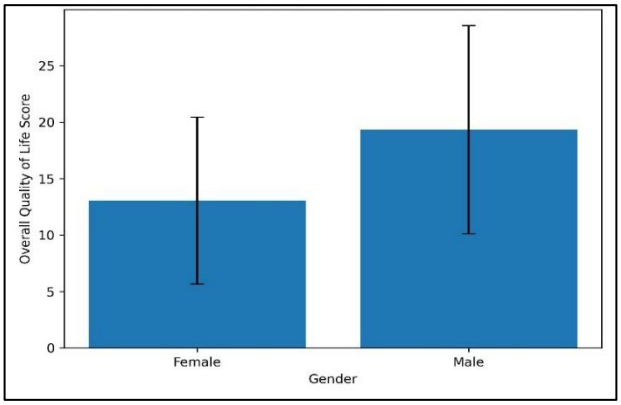

Figure 2: Comparison of overall quality of life scores between male and female children.

An analysis of the association between overall quality of life and gender revealed a statistically significant difference. Male children demonstrated higher quality of life scores compared to female children. The mean QoL score among males was 19.33±9.22, whereas females had a mean score of 13.05±7.40. This difference was found to be statistically significant (p=0.024), indicating better perceived quality of life among male participants. Gender-wise comparison of quality-of-life scores is shown in Table 3 and illustrated in Figure 2.

Table 4: Correlation between quality of life and anthropometric variables.

Variables	r value	P value
Age	–0.050	0.760
Height	0.298	0.062
Weight	0.081	0.621
BMI	–0.271	0.090

Correlation analysis was performed to examine the association between overall quality of life scores and age, height, weight, and BMI. No statistically significant correlations were observed between quality of life and age (r=–0.050, p=0.760), height (r=0.298, p=0.062), weight (r=0.081, p=0.621), or BMI (r=–0.271, p=0.090). These

findings suggest that anthropometric variables were not significantly associated with quality of life in the studied population. The correlation analysis is presented in Table 4.

DISCUSSION

This cross-sectional study evaluated the quality of life (QoL) of children aged 8-12 years with thalassemia using the parent-proxy pediatric quality of life inventory (PedsQL) 4.0 and demonstrated significant impairments across multiple domains. The findings indicate that children with thalassemia experience substantial limitations in physical, emotional, social, and school functioning, reflecting the multidimensional burden imposed by this chronic haematological disorder. These results reinforce the understanding that thalassemia affects not only haematological health but also functional ability and participation in daily life activities.[1-5]

The most pronounced impairment in this study was observed in the physical functioning domain. Chronic anaemia, reduced oxygen-carrying capacity, and recurrent transfusion requirements are known to result in fatigue, reduced endurance, muscle weakness, and exercise intolerance in children with thalassemia.[3-5] Additionally, frequent hospital visits and prolonged periods of inactivity may contribute to physical deconditioning and reduced participation in age-appropriate activities. From a physiotherapy perspective, these findings emphasize the importance of incorporating functional assessment, endurance training, graded exercise programs, and posture correction into the routine management of children with thalassemia to enhance physical capacity and independence.

Social functioning was also notably compromised in the present study. Recurrent absenteeism from school due to transfusions, visible physical differences, and activity restrictions may limit peer interaction and social participation. Previous studies have reported similar social and psychosocial challenges in children with thalassemia, highlighting the impact of long-term treatment burden and chronic illness on social integration and emotional well-being.[8,9] Rehabilitation professionals, including physiotherapists, can play a key role in facilitating participation through activity-based interventions, play therapy, and school reintegration strategies.

A statistically significant gender difference in overall QoL was identified, with male children demonstrating higher scores compared to female children. This finding is consistent with earlier reports suggesting that female children with thalassemia may experience greater emotional distress, social restrictions, and treatment-related fatigue, possibly influenced by sociocultural factors and caregiving dynamics.[8,9] Addressing these disparities requires gender-sensitive psychosocial support and individualized rehabilitation approaches to ensure equitable care and improved outcomes.

The absence of significant associations between QoL and age, height, weight, or body mass index suggests that quality of life in children with thalassemia is influenced more by disease-related factors and treatment demands than by anthropometric parameters alone. This observation aligns with existing literature emphasizing the role of disease severity, transfusion frequency, iron overload, and treatment adherence as key determinants of health-related quality of life.[1-6] These findings further support the need for a holistic, multidisciplinary approach that integrates medical management with physiotherapy and psychosocial interventions.

The results of this study highlight the crucial role of physiotherapy in the comprehensive management of pediatric thalassemia. Physiotherapy interventions can address physical impairments such as reduced endurance, muscle weakness, postural abnormalities, and activity limitations. Structured exercise programs, breathing exercises, functional training, and education on energy conservation may contribute to improved physical functioning and overall quality of life. Additionally, physiotherapists can support psychosocial well-being by encouraging participation in age-appropriate activities and promoting independence.

This study was conducted at a single centre with a relatively small sample size, which may limit the generalizability of the findings. The use of parent-proxy reports alone may introduce reporting bias, as children's self-reported perceptions of quality of life were not assessed. Furthermore, the cross-sectional design precludes evaluation of causal relationships or changes in quality of life over time.

Future scope

Future research should focus on multicentre longitudinal studies incorporating both parent-proxy and child self-report measures of quality of life. Including clinical indicators such as transfusion frequency, serum ferritin levels, and disease severity may provide a more comprehensive understanding of factors influencing quality of life. Interventional studies evaluating the effectiveness of physiotherapy-led rehabilitation programs in improving functional outcomes and quality of life are also warranted.

CONCLUSION

This study demonstrated that children aged 8-12 years with thalassemia experience substantial impairments in health-related quality of life across physical, emotional, social, and school functioning domains. Physical and social functioning were the most affected areas, highlighting limitations in daily activities and participation. The observed gender difference, with lower quality of life scores among female children, underscores the need for gender-sensitive psychosocial support. These findings advance understanding of the multidimensional impact of

thalassemia in childhood and emphasize the importance of integrating physiotherapy and multidisciplinary rehabilitation approaches alongside routine medical management to improve functional outcomes and overall quality of life.

ACKNOWLEDGEMENTS

The authors sincerely thank the management of RV College of Physiotherapy, Bengaluru, and the authorities of Samraksha- Thalassemia Day Care Centre, Bengaluru, for their support and cooperation during the study. The authors also express their gratitude to the children and their parents/caregivers for their willing participation.

Funding: No funding sources
Conflict of interest: None declared
Ethical approval: The study was approved by the Institutional Ethics Committee

REFERENCES

1. Weatherall DJ, Akinyanju O, Fucharoen S, Olivieri NF. Inherited disorders of hemoglobin. In: Jamison DT, Breman JG, Measham AR, eds. Disease Control Priorities in Developing Countries. 2nd ed. Washington (DC): World Bank; 2006:663-680.
2. Ministry of Health and Family Welfare, Government of India. Prevention and Control of Hemoglobinopathies in India- Thalassemia, Sickle Cell Disease and Other Variant Hemoglobins. New Delhi: National Health Mission; 2016.
3. Choudhry VP, Arora JS. Thalassemia. In: Gupta P, Menon PSN, Ramji S, Lodha R, eds. PG Textbook of Paediatrics. Vol. 2. New Delhi: Jaypee Brothers Medical Publishers; 2018:1556-1565.
4. Firkin F, Chesterman C, Penington D, Rush B. De Gruchy's Clinical Haematology in Medical Practice. 5th ed. Oxford: Blackwell Scientific Publications; 1989.
5. Rund D, Rachmilewitz E. Beta-thalassemia. N Engl J Med. 2005;353(11):1135-46.
6. Cappellini MD, Cohen A, Porter J, Taher A, Viprakasit V. Guidelines for the Management of Transfusion Dependent Thalassaemia (TDT). 3rd ed. Nicosia: Thalassaemia International Federation; 2014.
7. Varni JW, Seid M, Kurtin PS. PedsQL™ 4.0: reliability and validity of the Pediatric Quality of Life Inventory™ Version 4.0 Generic Core Scales in healthy and patient populations. Med Care. 2001;39(8):800-12.
8. Sharma S, Seth B, Jawade P, Ingale M, Setia MS. Quality of life in children with beta-thalassemia major: a cross-sectional study. Indian J Pediatr. 2017;84(6):475-80.
9. Thavorncharoensap M, Torcharus K, Nuchprayoon I, Riewpaiboon A, Indaratna K, Ubol BO. Factors affecting health-related quality of life in Thai children with thalassemia. BMC Hematol. 2010;10(1):1.

Cite this article as: Nadgir A, Wajapey P, Samaja YSS, Ramya SK. Health-related quality of life in children aged 8-12 years with thalassemia: a cross-sectional study using the pediatric quality of life inventory PedsQL. Int J Res Med Sci 2026;14:1046-50.