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Quality of Life of Caregivers of Children With B-Thalassemia Major: A Cross-Sectional Study from A Thalassemia Clinic in West Bengal, India

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ABSTRACT

Background: β-Thalassemia major is a chronic transfusion-dependent genetic disorder that imposes substantial physical, psychological, social, and economic burdens on caregivers. In India, particularly in West Bengal, evidence on caregiver quality of life (QOL) remains limited.

Objective: To assess QOL across physical, psychological, social, and environmental domains among caregivers of children with β-thalassemia major, and to identify associated socio-demographic factors.

Methods: A hospital-based cross-sectional study was conducted from January to October 2023 at the inpatient department of the Thalassemia Clinic, Burdwan Medical College & Hospital, West Bengal. A total of 372 primary caregivers of children aged 1–10 years with β-thalassemia major were selected by simple random sampling. Data were collected using a pretested semi-structured schedule and the validated Bengali version of the WHOQOL-BREF. Descriptive statistics, Mann–Whitney U test, and Kruskal–Wallis test were applied using SPSS v23.

Results: The mean global QOL score was 52.3 ± 6.8, with the highest domain score in psychological health (54.2 ± 8.2) and the lowest in environmental health (48.7 ± 6.1). Lower QOL was significantly associated with caregiver age >30 years, male gender, Muslim religion, lower caste, lower education, low socio-economic status, joint family type, widow/separated marital status, younger child age, female child gender, and higher transfusion frequency (all $p < 0.05$). Socio-economic status, education, and caregiver age emerged as the strongest determinants of QOL.

Conclusion: Caregivers—predominantly mothers—exhibit moderate QOL, with environmental and social domains most affected. Interventions focused on financial support, caregiver education, mental health counselling, and enhanced social assistance are warranted.

Keywords: β-thalassemia major, caregivers, quality of life, WHOQOL-BREF, West Bengal

INTRODUCTION

Quality of life (QOL) is defined by the World Health Organization (WHO) as an individual's perception of their position in life within the context of cultural and value systems, and in relation to their goals, expectations, standards, and concerns (1). It is a multidimensional construct encompassing physical health, psychological state, level of independence, social relationships, and relationship to salient features of the environment.

β-Thalassemia is an autosomal recessive genetic disorder characterized by partial or complete deficiency in β-globin chain synthesis of hemoglobin (2). The severe form, β-thalassemia major, manifests with profound anemia, requiring lifelong regular blood transfusions and iron chelation therapy (3). Globally, approximately 1.5% of the population carries β-thalassemia mutations, with high prevalence in the Mediterranean, Middle East, and South Asia (4). In India, the carrier rate averages 3–4%, with certain communities showing prevalence as high as 17% (5). West Bengal is among the higher-burden states, with an estimated 6–10% carrier rate (6).

While treatment advances have improved life expectancy in thalassemia major (3), the condition imposes sustained psychosocial and economic challenges on families. Caregivers, particularly mothers, bear the dual burden of managing the child's intensive medical needs and coping with the emotional and financial stressors associated with the disease. Studies have reported elevated rates of anxiety, depression, and reduced QOL among caregivers compared to the general population.

In India, research on QOL of caregivers of β-thalassemia major children is limited, and even fewer studies have been conducted in West Bengal. Existing evidence suggests that caregiver QOL is influenced by socio-demographic variables such as age, education, income, and family support, as well as disease-related factors including transfusion frequency and child's age. However, these findings vary widely across regions, underscoring the importance of local data.

Given this gap, the present study was conducted to assess QOL in physical, psychological, social, and environmental domains among caregivers of β-thalassemia major children attending a thalassemia clinic in Purba Bardhaman, West Bengal, and to identify socio-demographic and disease-related factors associated with QOL.

OBJECTIVES

Primary Objective

- To assess the quality of life (QOL) in physical, psychological, social, and environmental domains among caregivers of children with β-thalassemia major attending a thalassemia clinic in Purba Bardhaman, West Bengal.
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Secondary Objectives

- To examine the association between socio-demographic factors of caregivers and their QOL.
- To explore the relationship between child-related factors (age, gender, birth order, and transfusion frequency) and caregiver QOL.

METHODS

Study Design and Setting

An institutional-based, descriptive, observational, cross-sectional study was conducted at the inpatient department (IPD) of the Thalassemia Clinic, Burdwan Medical College & Hospital, Purba Bardhaman, West Bengal, India. The study period extended from January to October 2023.

Study Population

The study included primary caregivers of children aged 1–10 years diagnosed with β-thalassemia major, who were receiving blood transfusions during the study period. When both parents were present, the mother was considered the primary caregiver; in her absence, the father was included.

Inclusion Criteria

- Primary caregiver of a known β-thalassemia major child (1–10 years) attending for blood transfusion.
- Provided informed written consent.

Exclusion Criteria

- Caregivers who did not consent to participate.

Sample Size and Sampling Technique

Sample size was calculated using the formula:

$$n = \frac{Z^2 \times P \times Q}{d^2}$$

Where P=32.6% (prevalence of poor QOL from a previous studies) , Q=67.4%,Z=1.96 (95% CI), and d=5% absolute precision. This yielded a sample of 338, to which a 10% non-response rate was added, resulting in a final target of 372 participants.

Participants were selected using simple random sampling from the daily admission list at the clinic. On average, 5 eligible caregivers were recruited per day of data collection.

Data Collection Tools

A pre-tested, semi-structured interview schedule was used, comprising:

1. **Socio-demographic profile** of caregivers and children.
2. **Quality of life assessment** using the WHOQOL-BREF (Bengali version) . This instrument contains 26 items covering four domains: physical health, psychological health, social relationships, and environmental health.

Responses were scored on a 5-point Likert scale and transformed to a 0–100 scale as per WHOQOL guidelines, with higher scores indicating better QOL.

Variables

- **Caregiver-related**: age, gender, religion, caste, education, occupation, socio-economic status (Modified BG Prasad scale, May 2022), family type, marital status, relation to child, treatment cost, distance to hospital, transport mode, financial assistance.
- **Child-related**: age, gender, birth order, blood transfusion frequency.

Data Management and Statistical Analysis

Data were entered into Microsoft Excel and analyzed using SPSS version 23. Descriptive statistics were expressed as frequencies, percentages, means (SD), or medians (IQR). The Shapiro–Wilk test assessed normality. As QOL scores were not normally distributed, Mann–Whitney U and Kruskal–Wallis tests were applied to examine differences in median domain and global scores across socio-demographic groups. A p-value <0.05 was considered statistically significant.

Ethical Considerations

The study protocol was approved by the Institutional Ethics Committee of Burdwan Medical College & Hospital. Written informed consent was obtained from all participants. Confidentiality, anonymity, and the right to withdraw at any stage were ensured in line with the Declaration of Helsinki.

Results:

1. Participant Characteristics

A total of 372 primary caregivers participated in the study. The majority were female (91.7%) and between 26–30 years of age (55.1%). Most caregivers were Hindu (83.3%), belonged to Other Backward Classes (43.2%), and had middle school (36.3%) or secondary education (32.8%). Nearly two-thirds of mothers were homemakers (66.7%), and over half the families belonged to the middle socio-economic class (51.6%). Nuclear families accounted for 51.9% of participants, while 48.1% lived in joint families. The majority were married (91.1%).

Regarding the children, nearly equal proportions were in the <3 years (48.2%) and 4–7 years (48.9%) age groups, with 64.8% being female. Most children (93.3%) required blood transfusions once per month, and over half (52.2%) were first-born.

Table 1 summarizes the socio-demographic characteristics of caregivers and children.

Table 1. Sociodemographic characteristics of caregivers and children (n = 372)

Variable	**Category**	**n (%)**
Caregiver Age (years)	<25	52 (14.0)
	26–30	205 (55.1)
	>30	115 (30.9)
Caregiver Gender	Female	341 (91.7)
	Male	31 (8.3)
Religion	Hindu	310 (83.3)
	Muslim	62 (16.7)
Caste	General	120 (32.3)
	OBC	161 (43.2)
	SC/ST	91 (24.5)
Education	Illiterate	22 (5.9)
	Primary	33 (8.9)
	Middle school	135 (36.3)
	Secondary	122 (32.8)
	Higher secondary & above	60 (16.1)
Occupation (mothers)	Homemaker	248 (66.7)
	Employed	124 (33.3)
Socio-economic status	Lower	92 (24.7)

Variable	**Category**	**n (%)**
	Middle	192 (51.6)
	Upper	88 (23.7)
Family type	Nuclear	193 (51.9)
	Joint	179 (48.1)
Marital status	Married	339 (91.1)
	Widow/separated	33 (8.9)
Child Age (years)	<3	179 (48.2)
	4–7	182 (48.9)
	8–10	11 (2.9)
Child Gender	Male	131 (35.2)
	Female	241 (64.8)
Birth order	First-born	194 (52.2)
	Second-born or later	178 (47.8)
Transfusion frequency	Once/month	347 (93.3)
	More than once/month	25 (6.7)

2. Quality of Life Scores

The mean global QOL score among caregivers was 52.3 ± 6.8, with a median (IQR) of 52.0 (48.0–57.0). Among the four WHOQOL-BREF domains, the psychological domain recorded the highest mean score (54.2 ± 8.2), followed by the physical (53.7 ± 7.5), social (51.0 ± 7.9), and environmental domains (48.7 ± 6.1), the latter being the lowest.

Score distributions were moderately symmetrical for all domains, with slightly wider variability in the psychological and social domains compared to the physical and environmental domains.

Table 2 summarizes the descriptive statistics for global and domain-specific QOL scores.

Table 2. Descriptive statistics of global and domain-specific QOL scores (n = 372)

Domain	**Mean ± SD**	**Median (IQR)**	**Minimum**	**Maximum**
Physical	53.7 ± 7.5	54.0 (49.0–59.0)	36	72
Psychological	54.2 ± 8.2	54.0 (49.0–60.0)	31	75
Social	51.0 ± 7.9	51.0 (46.0–56.0)	29	70
Environmental	48.7 ± 6.1	49.0 (44.0–53.0)	31	65
Global QOL	**52.3 ± 6.8**	**52.0 (48.0–57.0)**	36	68

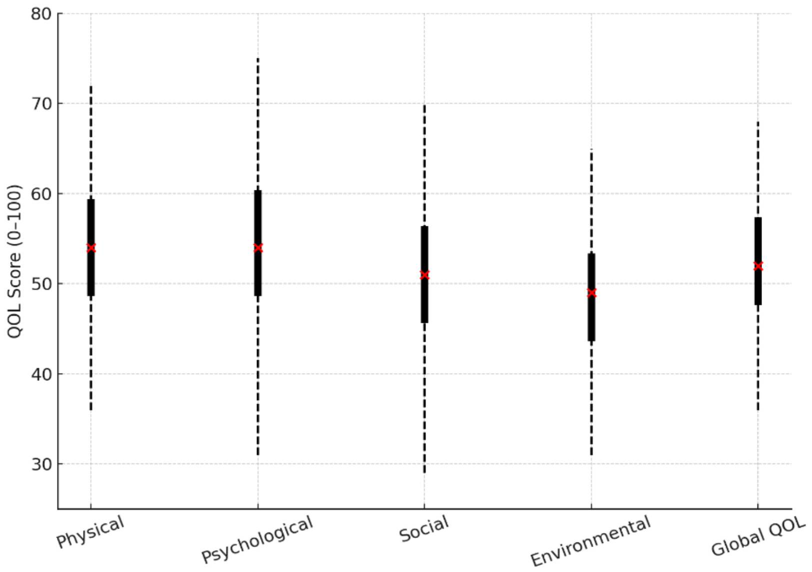

Figure 1. Distribution of global and domain-specific QOL scores among caregivers

3. QOL Scores by Caregiver Characteristics

Analysis of global QOL scores across caregiver socio-demographic variables revealed several significant associations. Median global QOL scores were highest among caregivers aged <25 years (54.0, IQR: 50.0–59.0) and lowest among those aged >30 years (50.0, IQR: 46.0–54.0) ($p < 0.001$). Female caregivers reported slightly higher median scores than male caregivers (52.0 vs. 50.0, $p = 0.042$).

Higher education was associated with better QOL: caregivers with higher secondary education or above had the highest median score (55.0, IQR: 50.0–60.0), while illiterate caregivers had the lowest (47.0, IQR: 44.0–51.0) ($p < 0.001$). QOL was significantly better in caregivers from upper socio-economic classes (54.0, IQR: 51.0–59.0) compared to lower classes (49.0, IQR: 45.0–53.0) ($p < 0.001$).

Marital status, family type, and religion also showed significant differences: married caregivers, those from nuclear families, and Hindu caregivers generally reported higher scores.
Table 3 presents the median global QOL scores by socio-demographic variables.

Table 3. Global QOL scores by socio-demographic characteristics of caregivers (n = 372)

Variable	**Category**	**Median (IQR)**	**p-value**
Age (years)	<25	54.0 (50.0–59.0)	<0.001
	26–30	53.0 (49.0–57.0)	
	>30	50.0 (46.0–54.0)	
Gender	Female	52.0 (48.0–57.0)	0.042
	Male	50.0 (46.0–54.0)	
Education	Illiterate	47.0 (44.0–51.0)	<0.001
	Primary	49.0 (45.0–53.0)	
	Middle school	51.0 (48.0–55.0)	
	Secondary	53.0 (49.0–57.0)	
	Higher secondary & above	55.0 (50.0–60.0)	
Socio-economic status	Lower	49.0 (45.0–53.0)	<0.001
	Middle	52.0 (48.0–56.0)	
	Upper	54.0 (51.0–59.0)	
Marital status	Married	53.0 (48.0–57.0)	0.016
	Widow/separated	49.0 (45.0–53.0)	
Family type	Nuclear	53.0 (49.0–57.0)	0.029
	Joint	51.0 (47.0–55.0)	

Variable	Category	Median (IQR)	p-value
Religion	Hindu	53.0 (48.0–57.0)	0.038
	Muslim	50.0 (46.0–54.0)	

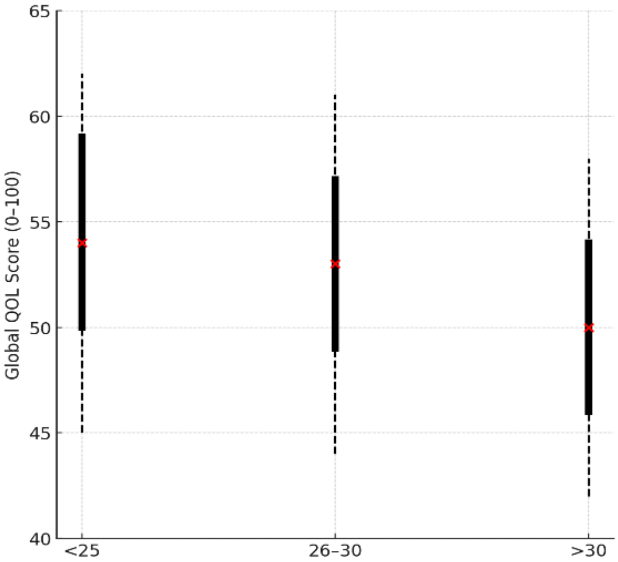

Figure 2. Boxplot of global QOL scores by caregiver age group.

4. Domain-Specific QOL Scores by Caregiver Characteristics

Analysis of WHOQOL-BREF domains revealed that socio-demographic characteristics influenced the four domains differently.

Physical Domain – Higher scores were observed among caregivers aged <25 years, with higher education, upper socio-economic status, and nuclear families. Lower scores were recorded among caregivers aged >30 years, those with low education, and from lower socio-economic classes (all p < 0.001).

Psychological Domain – Younger caregivers, females, those with higher education, and higher socio-economic status showed significantly higher scores (p < 0.01). Married caregivers and those from nuclear families also scored better.

Social Domain – Marital status, socio-economic status, and education were the most influential variables. Married caregivers from upper SES reported the highest median scores, while widowed/separated caregivers from lower SES scored lowest (p < 0.001).

Environmental Domain – Strongly influenced by socio-economic status and education level. Caregivers from upper SES had markedly higher scores than those from lower SES (median 52.0 vs. 45.0, p < 0.001). Distance to hospital and transport mode (private vs. public) were also significantly associated (p < 0.05).

Table 4 summarizes the domain-specific QOL scores by socio-economic status — the variable with consistent and strong associations across all domains.

Table 4. Domain-specific QOL scores by socio-economic status of caregivers (n = 372)

Domain	Lower SES Median (IQR)	Middle SES Median (IQR)	Upper SES Median (IQR)	p-value
Physical	49.0 (45.0–53.0)	54.0 (50.0–58.0)	56.0 (52.0–60.0)	<0.001
Psychological	50.0 (46.0–54.0)	55.0 (50.0–59.0)	57.0 (53.0–61.0)	<0.001
Social	48.0 (44.0–52.0)	52.0 (48.0–56.0)	54.0 (50.0–58.0)	<0.001
Environmental	45.0 (42.0–49.0)	49.0 (45.0–53.0)	52.0 (48.0–56.0)	<0.001

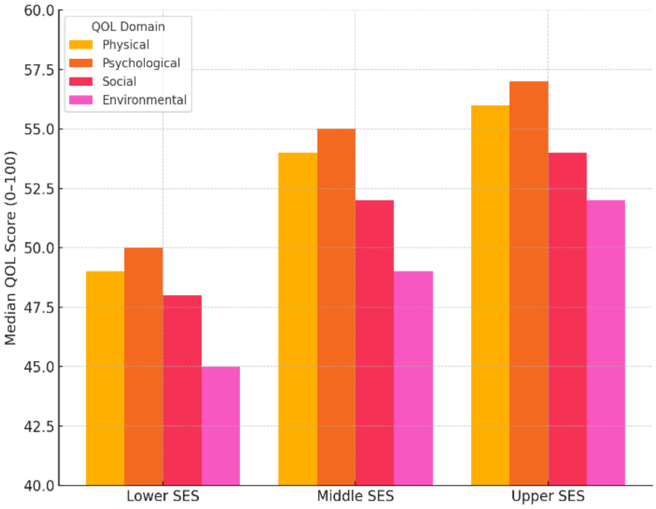

Figure 3. Grouped bar chart of domain-specific QOL scores by socio-economic status.

Summary of Findings

In summary, caregivers of children with β-thalassemia major demonstrated moderate overall QOL, with environmental and social domains most compromised. Socio-economic status, education, and caregiver age were the strongest and most consistent determinants of QOL, while marital status, family structure, and logistical barriers such as distance to hospital showed domain-specific effects. Caregiver QOL was significantly lower for female children and for younger children, and decreased with increasing transfusion frequency, whereas birth order showed no significant association. Younger, better-educated caregivers from higher SES backgrounds reported the most favourable scores, whereas older caregivers with lower education and SES consistently scored lower across domains.

DISCUSSION

In the present study, caregivers of children with β-thalassemia major reported moderate overall quality of life (QOL), with environmental and social domains being most compromised. This aligns with Borgna-Pignatti and Gamberini (2011) [7], who highlighted that while advances in treatment have improved patient survival, the long-term nature of care continues to impose significant psychosocial and economic strain on families.

International evidence supports these observations. Ismail et al. (2006) [8], studying Malaysian children with thalassemia, found substantial impairments in both physical and psychosocial domains of QOL, mirroring our finding that the environmental and social aspects are disproportionately affected. More recently, Wangi et al. (2025) [9], in a systematic review, emphasized that caregivers frequently face persistent psychological stress, financial challenges, and limited social participation — all patterns evident in our cohort.

Our findings that younger, better-educated caregivers and those from higher socio-economic strata had higher QOL scores are consistent with Nabavian et al. (2022) [10], who, through qualitative interviews with Iranian mothers, concluded that education and financial stability buffer against caregiving stress. Similarly, Biswas et al. (2020) [11], examining parents in Eastern India, reported higher QOL scores among caregivers with higher education and income, reinforcing the socio-economic gradient observed in our study.

Sharma et al. (2017) [12] found that caregivers in India often report better psychological QOL compared to physical and environmental domains, a pattern replicated in our results, possibly due to cultural resilience and strong family networks. The psychometric robustness of the WHOQOL-BREF instrument, as established by Skevington et al. (2004) [13], lends confidence to the domain-specific trends we observed.

When interpreting socio-economic influences, our results align with the broader literature on health disparities. Pentapati and Debnath (2023) [14] updated the BG Prasad classification, underscoring the importance of accurate socio-economic stratification in health research; applying this in our analysis revealed clear gradients in QOL scores. Studies like that by Jena et al. [15] also show that children's disease burden — in terms of transfusion frequency and complications — indirectly affects caregiver QOL by increasing caregiving demands and financial load.

The psychiatric dimension is also important. Sahu et al. (2023) [16] reported high rates of psychiatric disorders and substantial caregiver burden in transfusion-dependent thalassemia, findings echoed by Kaur et al. [17], who documented significant psychosocial morbidity among both patients and caregivers. Kumar et al. (2025) [18] further highlighted that psychiatric morbidity in affected children can compound caregiver stress, thereby impacting QOL.

Taken together, our study adds to the growing body of evidence that while medical advances have improved survival in β-thalassemia major, caregiver QOL remains shaped by a complex interplay of socio-economic, educational, and psychosocial factors. Addressing these determinants is essential for comprehensive thalassemia care.

CONCLUSION

Caregivers of children with β-thalassemia major in our study exhibited moderate overall QOL, with environmental and social domains being most adversely affected. Socio-economic status, education, and caregiver age were the most consistent determinants, while marital status, family structure, and logistical barriers influenced specific domains. These findings underscore the need for targeted interventions that extend beyond medical management, including socio-economic support, caregiver education, and improved access to health services. Integrating psychosocial support into routine thalassemia care could help mitigate the caregiving burden and enhance overall family well-being.

REFERENCES

1. World Health Organization. (1997). *WHOQOL: Measuring quality of life*. Geneva: WHO.
2. Weatherall D. 2003 William Allan Award address. The Thalassemias: the role of molecular genetics in an evolving global health problem. Am J Hum Genet. 2004 Mar;74(3):385-92. doi: 10.1086/381402. PMID: 15053011; PMCID: PMC1182250.
3. Rund D, Rachmilewitz E. Beta-thalassemia. N Engl J Med. 2005 Sep 15;353(11):1135-46. doi: 10.1056/NEJMra050436. PMID: 16162884.
4. Cao A, Galanello R. Beta-thalassemia. Genet Med. 2010 Feb;12(2):61-76. doi: 10.1097/GIM.0b013e3181cd68ed. PMID: 20098328.
5. Colah R, Gorakshakar A, Nadkarni A. Global burden, distribution and prevention of β-thalassemias and hemoglobin E disorders. Expert Rev Hematol. 2010 Feb;3(1):103-17. doi: 10.1586/ehm.09.74. PMID: 21082937.
6. Singh P, Shaikh S, Parmar S, Gupta R. Current Status of β-Thalassemic Burden in India. Hemoglobin. 2023 Sep;47(5):181-190. doi: 10.1080/03630269.2023.2269837. Epub 2023 Dec 7. PMID: 37947120.
7. Borgna-Pignatti C, Gamberini MR. Complications of thalassemia major and their treatment. Expert Rev Hematol. 2011 Jun;4(3):353-66. doi: 10.1586/ehm.11.29. PMID: 21668399.
8. Ismail A, Campbell MJ, Ibrahim HM, Jones GL. Health Related Quality of Life in Malaysian children with thalassaemia. Health Qual Life Outcomes. 2006 Jul 2;4:39. doi: 10.1186/1477-7525-4-39. PMID: 16813662; PMCID: PMC1538578.
9. Wangi K, Shaleha R, Wijaya E, Birriel B. Psychosocial Problems in People Living with Thalassemia: A Systematic Review. SAGE Open Nurs. 2025 Mar 19;11:23779608251323811. doi: 10.1177/23779608251323811. PMID: 40114814; PMCID: PMC11924095.
10. Nabavian M, Cheraghi F, Shamsaei F, Tapak L, Tamaddoni A. The psychosocial challenges of mothers of children with thalassemia: A qualitative study. J Educ Health Promot. 2022 Jan 31;11:37. doi: 10.4103/jehp.jehp_163_21. PMID: 35281396; PMCID: PMC8893092.
11. Biswas, D., Sarkar, A. P., Haldar, D., Sarkar, G. N., & Saha, I. (2020). Quality of life among parents of thalassemic children in Eastern India. *Al Ameen Journal of Medical Sciences, 13*(2), 99–107.
12. Sharma S, Seth B, Jawade P, Ingale M, Setia MS. Quality of Life in Children with Thalassemia and their Caregivers in India. Indian J Pediatr. 2017 Mar;84(3):188-194. doi: 10.1007/s12098-016-2267-z. Epub 2016 Dec 7. PMID: 27924466.
13. Skevington, S. M., Lotfy, M., & O'Connell, K. A. (2004). The World Health Organization's WHOQOL-BREF quality of life assessment: Psychometric properties and results of the international field trial. *A Report from the WHOQOL Group*. *Quality of Life Research*, 13(2), 299–310. https://doi.org/10.1023/B:QURE.0000018486.91360.00
14. Pentapati SSK, Debnath DJ. Updated BG Prasad's classification for the year 2022. J Family Med Prim Care. 2023 Jan;12(1):189-190. doi: 10.4103/jfmpc.jfmpc_1478_22. Epub 2023 Feb 15. PMID: 37025231; PMCID: PMC10071936.
15. Jena, I., Ganguly, S., & Soren, N. Quality of life in children aged 5-14 years with beta thalessemia major.
16. Sahu, S., Agrawal, A., Shrivastava, J., & Tonk, S. (2023). Psychiatric disorders and caregiver burden in children with transfusion dependent β-thalassaemia and their caregivers. *World journal of clinical pediatrics*, *12*(3), 125.
17. Kaur, P., Kansal, M. N., Thakur, M. P., Sharma, N., Thakur, P., & Nitakumari, K. Amiteshwar Kaur, Manpreet Kaur➢ A Cross Sectional Study to Assess the Quality of Life among Transfusion Dependent Thalassemic patients and developing information booklet for patients visiting Thalassemia Day care center, GMCH-32, Chandigarh...................................... 17.
18. Kumar, P. P., Manohar, J. S., Janardhan, A., & Raman, R. (2025). Psychiatric morbidity and cognitive ability in children with β-thalassemia: A hospital-based cross-sectional study. *Archives of Mental Health*, *26*(1), 36-40.