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Key factors affecting psychosocial well-being in thalassemic children from eastern India: an institutional study

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ABSTRACT

Background: Thalassemia syndromes, prevalent in Eastern India, significantly impact the psychosocial health of affected children. The challenges associated with chronic treatment and disease management underscore the need for comprehensive quality of life assessments.

Methods: This cross-sectional study was conducted at Bankura Sammilani Medical College and Hospital from July 2022 to June 2023. A sample of 371 thalassemic children aged 5-12 was analyzed using the Pediatric Quality of Life Inventory 4.0 Generic Core Scale. Socio-demographic data and psychosocial health were evaluated through parent interviews and clinical records. Statistical analyses included correlation and regression models to identify factors influencing psychosocial health.

Results: The mean psychosocial health summary score was 63 (SD=9.4), indicating significant psychosocial challenges. Key factors associated with better psychosocial outcomes included lower duration of blood transfusions, female gender, positive family history of thalassemia, and higher socioeconomic status. The regression analysis revealed that these factors collectively explained 21.3% of the variability in psychosocial health scores.

Conclusion: The study emphasizes the critical influence of gender, family history, socioeconomic status, and transfusion duration on the psychosocial well-being of thalassemic children. Integrated care approaches combining medical treatment with psychological support are essential for improving quality of life. Early intervention strategies, family support programs, and tailored treatment plans that consider gender-specific needs are recommended to address the emotional and social challenges faced by these children.

Keywords: Psychosocial health, Thalassemia, PedsQL, Blood transfusion

INTRODUCTION

Thalassemia syndromes encompass a diverse array of single-gene disorders inherited in an autosomal recessive manner, affecting various ethnicities and present in nearly every country globally.¹ In 2021, there were 1,310,407 thalassemia cases globally, with an age-standardized prevalence rate (ASPR) of 18.28 per 100,000 persons (95% uncertainty interval: 15.29–22.02).² In rural Bengal, the prevalence of hemoglobinopathies is as follows: β-thalassemia trait 6.61%, HbE trait 2.78%, sickle cell trait

0.56%, HbD-Punjab trait 0.21%, β-thalassemia major 0.73%, HbEE 0.05%, compound heterozygosity for HbE-β-thalassemia 0.42%, and HbS-β-thalassemia 0.15%.³ Hemoglobin (Hb) E/beta-Thalassemia is notably prevalent among Bengalis in Eastern India. Once diagnosed with thalassemia, children typically require lifelong treatment, which only 5-10% of thalassemic children in India can access. Given the chronic nature of Thalassemia without a cure and requiring prolonged treatment, assessing quality of life becomes crucial. Children often face challenges in expressing their concerns, underscoring the importance of

evaluating their quality of life to ensure proper care. This assessment helps identify the disease and treatment impacts from the children's perspective.^{4,6} Psychosocial well-being significantly influences their overall quality of life. The significant prevalence of mental health issues among thalassemia patients in both inpatient and outpatient settings highlights the urgent need to identify factors contributing to their psychosocial challenges. Thalassemia major patients often experience physical manifestations such as growth delays, splenomegaly, yellowish-bronze skin colour, and distinct facial features, which can deeply affect their self-esteem and sense of belonging.

Consequently, they may withdraw from social interactions, negatively impacting their mental health and overall quality of life. Those with low self-esteem and body image concerns are particularly susceptible to depression, affecting their interpersonal relationships. Anxiety about life expectancy and quality of life further compounds mental health issues among thalassemia patients.⁷

Studies indicate that children with thalassemia major are at heightened risk of developing anxiety and depression due to social isolation, physical changes, medication effects, restricted activities, educational limitations, and fear of mortality. The burden of recurrent blood transfusions and daily iron chelation therapy also contributes to depression directly related to disease management.^{8,9} These factors emphasize the unique challenges faced by thalassemia patients, impacting their mental health and societal integration.

This aspect has been notably overlooked by healthcare systems, with limited research available. Few studies have explored the factors impacting psychosocial health in children and adolescents with Thalassemia globally, and information specific to our region, including West Bengal, is notably sparse. Understanding these factors is crucial for designing targeted clinical, counselling, and social support interventions to enhance treatment outcomes and improve the quality of life for Thalassemia patients.

METHODS

Study type

This was a hospital-based cross-sectional analytical epidemiological study.

Study duration

The study was conducted between July 2022 and June 2023.

Study place

The study was conducted at Bankura Sammilani Medical College and Hospital, a tertiary care facility serving not

only Bankura district but also neighboring districts in West Bengal, India.

Inclusion criteria

The study included major or intermediate thalassemic patients aged 5 to 12 years admitted to the day care unit, solely for therapeutic blood transfusions and receiving such treatment regularly for at least 2 years.

Exclusion criteria

Exclusions were made for Thalassemic children who had suffered serious illness in the month prior to data collection, had impaired cognitive function, grossly delayed developmental milestones, or other chronic diseases. According to records and consultations with department heads, approximately 3615 Thalassemic children aged 5-12 were admitted to Bankura Sammilani Medical College and Hospital the previous year.

Each thalassemic patient in this age group received an average of 9 blood transfusions per year, as documented in hospital registers and records. Sample size is calculated using the following formula: $n = \frac{Z^2 \cdot P \cdot (1-P)}{E^2}$ (Where n = sample size, $Z= 1.96$ (at 95% CI) = standard deviation of overall QOL score of thalassemic children=9.3610, E = margin of error=1%) final sample size is 371 considering 10% non-response.

Data collection

Data collection occurred three days per week during the study period, with the specific days rotated weekly to mitigate bias from day-specific hospital admission rates. All thalassemic patients within the designated age group who were admitted on the days of data collection in their respective departments were included until the required sample size was achieved.

Parents of the children were interviewed using the pediatric quality of life inventory 4.0 generic core scale, parent proxy reports (age ranges: 5-7, 8-12), to gather socio-demographic characteristics and quality of life data.¹¹ Medical records (including laboratory reports, bed head tickets, old prescriptions, discharge certificates, etc.) were reviewed to collect clinico-therapeutic profiles of the study subjects.

Prior to implementation, the reliability and validity of this scale were assessed in our study setting using Cronbach's alpha test. Reliability analysis indicated good consistency for the physical, social, and school functioning scales, with Cronbach's α coefficients of 0.873, 0.805, and 0.911, respectively. The emotional scale demonstrated satisfactory reliability (Cronbach's α coefficient=0.626).

The psychosocial health summary score is derived by calculating the mean of the sum of items answered in the emotional, social, and school functioning scales, divided

by the number of items in these scales. If the child did not attend school, the scores from the remaining two domains are averaged according to their item numbers to determine the psychosocial health summary score. Permission to use the PedsQL 4.0 generic core scale in this unfunded research was granted by Mapi research trust.

Ethical approval

The study began after obtaining ethical clearance from the Institutional Ethics Committee, approval (BSMC/Aca: 812 dated 05/04/2022) from the In-charge of the respective departments at Bankura Sammilani Medical College, along with informed written consent from the parents of all participating children

Statistical analysis

All statistical analyses were performed using SPSS software, version 19.0 (IBM SPSS Statistics, Chicago, IL, USA). Differences between mean values were assessed using unpaired Student's t-test or Mann Whitney U test, while analysis of variance (ANOVA) or Kruskal Wallis test was utilized for comparisons involving more than two mean values as per applicability. Pearson's correlation coefficient (r) was computed to determine the degree and direction of relationships between variables. Partial correlation was also calculated to identify relationships between variables while controlling for other related variables. Variables showing significant correlations in partial correlation analyses were subsequently included in multiple linear regression models (stepwise approach) to assess changes in the dependent variable with a one-unit change in independent variables.

RESULTS

The study was conducted with a sample of 371 children diagnosed with thalassemia. The mean age of the participants was 8.28 years, with a standard deviation of 2.4 years. The cohort was predominantly male (51.5%) and primarily Hindu (59.6%). In terms of caste, the majority belonged to the General caste (56.3%). Most of the children lived in nuclear families (72%) and resided in rural areas (81.7%).

Socioeconomic status was predominantly lower class, affecting 69.5% of the participants. Consanguinity was

reported in 9.4% of the cases. The median frequency of blood transfusions was 12 per year, with an average duration of blood transfusion therapy spanning 6 years ($SD=2.46$). Additionally, 13.7% of the children had undergone splenectomy, and 24.5% were receiving treatment with chelating agents. The average psychosocial health summary score was 63 ($SD=9.4$), significantly below the highest possible score of 100 (Figure 1).

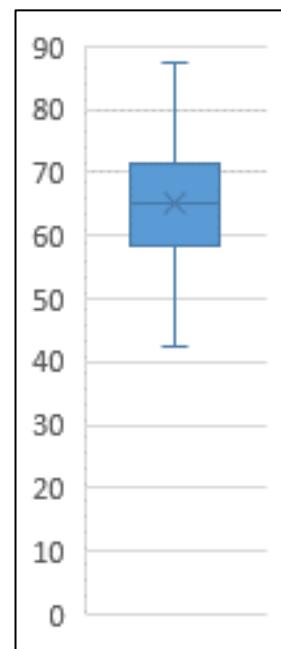


Figure 1: Box and whisker plot showing the distribution of psychosocial health summary score of thalassemic children.

In bivariate analysis psychosocial health summary score were found significantly better among 5 to 7 years aged child, female patients, absence of consanguineous marriage among parents, having Thalassemia patient within the family, lower and upper middle socio-economic status of the family, duration of blood transfusion less than 5 years, frequency of blood transfusion in the last year ≤ 6 years and splenectomy within 3 to 5 years. The sub-variables of significant categorical independent variables which were related with higher psychosocial health summary score were recoded as higher score and recoded scores were varied between 1 to 4 according to sub variables.

Table 1: Distribution of psychosocial health summary score according to socio-demographic factors and clinico-therapeutic profiles of the patient N=371.

Variables	Sub variable	Psychosocial health summary score	Test of significance	Effect size
Age	5-7 years	66.3 \pm 9.43	t= 2.29, df=369, p=0.022*	0.238
	8-12 years	64 \pm 9.33		
Gender	Male	63.1 \pm 8.76	Welch's t = -4.45, df=369, p \leq 0.001*	-0.463
	Female	67.3 \pm 9.65		

Continued.

Variables	Sub variable	Psychosocial health summary score	Test of significance	Effect size
Religion	Hindu	65.9±9.19	t=1.88, df=369, p=0.061	0.199
	Muslim	64±9.71		
Caste	General	64.3±9.3	F=2.59, p=0.079	0.0242
	SC	65.6±9.11		
	ST	67.9±10.48		
Residence	Rural	185 (mean rank)	Mann Whitney U= 10167, p=0.754	-0.0970
	Urban/Suburban	190 (mean rank)		
Family type	Joint	64.5±10.7	t= -0.841, df=369, p=0.401	0.176
	Nuclear	65.4±8.92		
History of Consanguineous marriage	Yes	156 (mean rank)	Mann Whitney U= 4719, p=0.09*	-0.546
	No	189 (mean rank)		
Family history of Thalassemia	Yes	69±7.71	t= -4.38, df=369, p≤0.001*	0.0590
	No	64±9.6		
Socio-economic status	Lower	153 (mean rank)	Kruskal Wallis test: χ^2 = 21.8, p≤0.001*	0.0231
	Upper lower	180 (mean rank)		
	Lower middle	221 (mean rank)		
	Upper middle	223 (mean rank)		
Education of parents a	Illiterate	178 (mean rank)	Kruskal Wallis test: χ^2 = 8.55, p=0.073	0.283
	Primary	204 (mean rank)		
	Secondary	189 (mean rank)		
	Higher secondary	254 (mean rank)		
	Graduates	101 (mean rank)		
Birth order	1	185 (mean rank)	Kruskal Wallis test: χ^2 = 5.92, p=0.052	0.0160
	2	198 (mean rank)		
	≥3	157 (mean rank)		
Last pre transfusion Hb level (g/dl)	<5 g/dl	61.5±8.55	F=12.4, p<0.001*	0.283
	5-7 g/dl	66.7±9.67		
	>7 g/dl	65.7±6.78		
Duration of blood transfusion	2-5 years	67±9.33	t= 2.52, df=369, p=0.012*	0.00380
	≥ 5 years	64.3±9.38		
Frequency of blood transfusion in the last year	1-6 times/ year	71±8.92	F= 21.1, p<0.001*	0.0159
	7-12 times/ year	66±8.80		
	>12 times/year	61.5±9.19		
History of hospitalization in the last year other than blood transfusion	Yes	172 (mean rank)	Mann Whitney U= 7184, p=0.313	0.0894
	No	188 (mean rank)		
History of splenectomy	Yes	180 (mean rank)	Mann Whitney U= 7737, p=0.682	0.0348
	No	187 (mean rank)		
Duration since splenectomy	≤2 years	146 (mean rank)	Kruskal Wallis test: χ^2 = 15.2, p≤0.001*	0.310
	3-5 years	171 (mean rank)		
	≥5 years	147 (mean rank)		
Any specific complication related to disease	Yes	182 (mean rank)	Mann Whitney U= 14070, p=0.593	0.00380
	No	188 (mean rank)		
History of receiving chelating agent	Yes	187 (mean rank)	Mann Whitney U= 12597, p=0.957	0.0159
	No	186 (mean rank)		
Type of Thalassemia (Only 115 data were available)	HbE—beta	60.9 (mean rank)	Kruskal Wallis test: χ^2 = 1.81, p≤0.405	0.0159
	Beta thalassemia major	53.7 (mean rank)		
	Beta thalassemia intermediate	63.6 (mean rank)		

*Statistically significant

Table 2: Correlation matrix and partial correlation between different independent variables and psychosocial health summary score.

	A	B	C	D	E	F	G	H	I
A	1								
B	0.013	1							
C	-0.178*	0.067	1						
D	-0.185*	-0.032	0.081	1					
E	-0.183*	0.131*	0.010	0.268*	1				
F	0.271*	0.174*	-0.131*	-0.066	-0.273*	1			
G	0.91	0.107*	0.004	0.071	0.061	0.202*	1	.	
H	0.208	-0.081	-0.080	-0.201	0.328*	-0.044	0.117	1	
I	0.118*	0.226*	0.090	0.222*	0.240*	0.130*	0.097	0.067	1
Discrete variables	Scores assigned								
		1			2		3		4
Age		8-12 years			5-7 years				
Gender		Male			Female				
Consanguineous marriage among parents		Yes			No				
Family history of Thalassemia		No			Yes				
Socio-economic status		Lower			Upper lower		Lower middle		Upper middle
Duration of blood transfusion		≥5 years			2-5 years				
Frequency of blood transfusion		>12 times/ year			7-12 times/year		1-6 times/year		
Duration since Splenectomy		≤2 years			≥5 years		3-5 years		
Duration since Splenectomy		≤2 years			≥5 years		3-5 years		
Duration since Splenectomy		≤2 years			≥5 years		3-5 years		

*Correlation is significant at the 0.05 level (2-tailed). ##Score assigned to different categorical variables for multifactorial analysis.

###Independent variables were used in correlation matrix. A= age, b= gender, c= consanguineous marriage of parents of thalassemic children, d= family history of thalassemia, e= socio-economic status, f= duration of blood transfusion, g= frequency of blood transfusion, h= duration since splenectomy, i= psychosocial health summary score.

Table 3: Multivariable linear regression model.

Model	R	R ²	Adjusted R ²	F	df1	df2	P value
1	0.2661	0.07080	0.0657	14.02	2	368	<0.001
2	0.3323	0.11044	0.1032	15.19	3	367	<0.001
3	0.4052	0.16419	0.1551	17.97	4	366	<0.001
4	0.4774	0.22796	0.2131	15.31	7	363	<0.001

1: Duration of blood transfusion, 2: Duration of blood transfusion, Gender, 3: Duration of blood transfusion, Gender, Family history of Thalassemia, 4: Duration of blood transfusion, gender, family history of thalassemia, socio-economic status.

In the correlation matrix, it was found that independent variables were inter related. So, to get the true relationship among independent variable and dependent variable, partial correlation was done. During partial correlation, one independent and one dependent variable were considered and remaining independent variables were kept in constant. In partial correlation, psychosocial health summary score positively correlated with age, gender, family history Thalassemia, socio-economic status and

duration of blood transfusion. Factors were found statistically significant in partial correlation considering for multivariable linear regression. All independent variables were checked for best fitted curves (linear, quadratic, cubic, exponential). Above independent variables were found significantly fitted in the linear curve and those were considered for multivariate linear regression. As tolerance score were above 0.2 and VIF score was below 10, multicollinearity was absent here. As

Durbin Watson value was closer to 2 (1.99), autocorrelation was absent here. It means that residuals were independent here. From the model summary it has found that ultimately duration of blood transfusion, gender, family history of thalassemia and socio-economic status explained 21.3 % variation of psychosocial health summary score. Socio-economic status, family history of Thalassemia, gender and duration of blood transfusion explained 5.8% (21.3%-15.5%), 5.2% (15.5%-10.3%), 3.7% (10.3%-6.6%) and 6.6% variation of psychosocial health summary score respectively. Regression equation was as psychosocial health summary score=65.838-1.384 (duration of blood transfusion) +2.973 (gender) +3.945 (family history of thalassemia) +6.436 (SES).

DISCUSSION

A hospital-based cross-sectional analytical epidemiological study was conducted at Bankura Sammilani Medical College and Hospital from July 2022 to June 2023 to assess the psychosocial well-being of thalassemic children in Eastern India. The study utilized the pediatric quality of life inventory 4.0 generic core scale, gathering data through interviews with parents to identify key factors affecting their children's well-being. The current study found that psychosocial summary scores tend to decline as the duration of blood transfusion therapy increases over the patient's lifetime.

A similar observation was made by Abdelaziz et al, in their study, where they also found that the psychosocial health of children with thalassemia is strongly influenced by the duration and frequency of their blood transfusions. Regular transfusions, which are necessary for managing the disease, contribute to emotional and psychological challenges such as anxiety, depression, social withdrawal, and somatic complaints. Studies indicate that children requiring frequent transfusions tend to exhibit higher rates of clinical anxiety and depressive symptoms compared to those with fewer transfusion needs.¹² Patil S, et al study showed that over 80% of children who had been undergoing transfusions for several years experienced significant psychosocial problems, including attention and behavioral issues.¹³

The length of time since diagnosis and the years of transfusion therapy are closely linked to a decline in quality of life, especially in terms of emotional well-being and school performance. As treatment continues over time, children face increasing emotional stress due to frequent hospitalizations, interrupted education, and feelings of isolation from their peers. These factors collectively contribute to a broader social impact.¹⁴ Studies from India and other regions highlight the significant impact of thalassemia on social, emotional, and school functioning, with scores in these areas often lower than in other chronic illnesses.¹⁴ In the current study, male thalassemic children were found to have lower psychosocial summary scores compared to their female counterparts. Research on the psychosocial health of children with thalassemia indicates

that both the gender of the child and the chronic nature of the condition play a significant role in shaping psychological outcomes. Studies show that children with thalassemia, regardless of gender, face emotional and social challenges such as anxiety, depression, and school-related issues. However, some research suggests that gender can influence the specific psychosocial burden experienced.^{15,16}

One study highlights that psychosocial health in both genders is deeply affected by factors like the frequency of hospitalizations, physical disfigurements due to the disease, and delayed puberty, which might affect boys and girls differently in terms of self-esteem and social relationships. The overall emotional burden tends to escalate with disease progression, but the way boys and girls express or cope with these challenges may differ due to cultural or psychological factors. For example, male children with thalassemia have been observed to exhibit a higher prevalence of behavioural issues and emotional disorders compared to females, potentially due to societal expectations or differences in coping mechanisms. On the other hand, females may experience more internalizing symptoms like anxiety and depression, though this varies across studies and cultural contexts. However, females tend to cope more effectively than males.¹⁷

Family history of thalassemia significantly impacts the psychosocial health of affected children, often leading to increased emotional and social challenges. Both Thalassemic children and their siblings may experience anxiety, depression, and social isolation, with the psychosocial issues being more pronounced in the affected children. These challenges are often compounded by financial strain and fears related to the disease.^{12,18}

But in this study, children with thalassemia who had a family history of the disease showed better psychosocial health than those without such a background, which contradicts findings from other research. Few researches indicate that the psychosocial health of children with thalassemia can be positively influenced by having a family history of the disease.

Understanding the condition within the family context can enhance coping mechanisms and support systems, ultimately leading to better emotional well-being for affected children. Studies have highlighted that familial support can mitigate common psychological issues like anxiety and depression, which are prevalent among thalassemic patients.¹⁶ The present study highlights that thalassemic children from higher socioeconomic backgrounds tend to have better psychosocial health. Specifically, children with higher family income in India reported improved quality of life and fewer psychosocial issues compared to those from lower-income families. This correlation underscores the significant impact of socioeconomic factors on health outcomes. Additionally, families with greater resources can offer enhanced

emotional support, educational opportunities, and create environments conducive to better mental health.¹⁵

CONCLUSION

The psychosocial health of eastern Indian children with thalassemia is significantly influenced by factors such as gender, family history of the disease, socioeconomic status, and the duration of blood transfusions. Children from higher socioeconomic backgrounds tend to experience better psychosocial outcomes, highlighting the critical role of access to resources like education and healthcare. To effectively manage the psychosocial health of thalassemic children, integrated care approaches should be adopted that encompass both medical treatment and psychological support. Early intervention strategies, including psychological counselling and family support programs, are essential to alleviate the emotional challenges associated with long-term transfusion therapy.

Additionally, treatment plans should consider gender-specific psychosocial responses to cater to the unique emotional needs of boys and girls. For families without a history of thalassemia, enhanced psychological support should be provided to help them navigate the social and emotional implications of the condition. Implementing early intervention programs and mental health screenings will aid in the timely identification and management of psychosocial issues.

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