

Original Research Article

Caregiver knowledge, socioeconomic challenges and treatment practices in pediatric thalassemia: experience from a resource-constrained setting

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ABSTRACT

Background: Transfusion-dependent thalassemia (TDT) requires lifelong blood transfusion and comprehensive supportive care. In resource-constrained settings, caregiver knowledge and socioeconomic factors may influence treatment adherence and clinical outcomes. This study assessed caregiver knowledge, treatment practices, socioeconomic challenges, and factors associated with blood transfusion adherence among children with TDT in Bangladesh.

Methods: A hospital-based cross-sectional study was conducted at the Institute of Child and Mother Health, Dhaka, Bangladesh, between July 2023 and June 2025. One hundred caregiver-child pairs were consecutively enrolled. Data were collected using a pretested structured interviewer-administered questionnaire and verified with hospital records where available. Blood transfusion adherence was categorized as regular or irregular. Multivariable binary logistic regression was performed to identify independent predictors of regular transfusion adherence.

Results: Among the 100 enrolled children, 65% had HbE/ β -thalassemia and 35% had β -thalassemia major. Regular blood transfusion adherence was observed in 56% of participants. Caregiver knowledge was generally inadequate: 82% had no prior awareness of thalassemia, only 4% knew all recommended treatment modalities, and satisfactory knowledge of nutritional management and disease complications was reported by 13% and 9%, respectively. Nevertheless, 78% expressed willingness to undergo family carrier screening. Most families (80%) financed treatment from their own income, while 17% relied on loans or begging. Paternal educational attainment below the primary level was independently associated with lower odds of regular blood transfusion adherence (adjusted OR 0.324, 95% CI 0.128-0.817; $p=0.017$).

Conclusions: In this study, caregiver knowledge regarding TDT was limited, and nearly half of the children did not receive regular blood transfusions (BT). Financial hardship remained common, with many families relying on loans or begging to sustain treatment. These findings support strengthening caregiver education, genetic counselling, and financial support for affected families.

Keywords: Transfusion-dependent thalassemia, Blood transfusion adherence, Caregiver knowledge, Chelation

INTRODUCTION

Thalassemia comprises a group of inherited hemoglobin disorders caused by reduced or absent synthesis of one or more globin chains, resulting in ineffective erythropoiesis, chronic hemolytic anemia, and variable clinical severity.¹ Children with TDT require lifelong

regular BT and iron chelation therapy to maintain adequate hemoglobin levels and prevent transfusion-related complications. Despite advances in treatment, thalassemia continues to impose substantial physical, psychological, and financial burdens on affected children and their families.^{2,3}

Globally, approximately 5% of the population carries a clinically significant hemoglobin disorder, and an estimated 50,000-60,000 children are born each year with severe β -thalassemia, the majority in low- and middle-income countries (LMIC).^{4,5} Bangladesh lies within the so-called "thalassemia belt" and has one of the highest burdens of hemoglobinopathies in South Asia.⁶ Recent national data indicate that 11.4% of the population carries at least one thalassemia-related hemoglobin variant, while previous estimates suggest that 17-22 million people are carriers and 6,000-8,000 affected children are born annually. The combination of a high prevalence of HbE and β -thalassemia, limited public awareness, inadequate carrier screening, and restricted access to comprehensive care continues to sustain this disease burden.⁶⁻⁸

Although advances in transfusion therapy and iron chelation have improved survival, successful long-term management depends heavily on caregivers. They are responsible for ensuring regular hospital visits, treatment adherence, nutritional support, recognition of complications, and decisions regarding carrier screening and genetic counseling. In resource-constrained settings, however, financial hardship, limited health literacy, and inadequate access to specialized services often compromise optimal care and contribute to poor treatment adherence.⁹⁻¹¹

Several studies from South Asia have reported inadequate caregiver knowledge regarding thalassemia and highlighted the financial and social challenges associated with lifelong treatment. However, evidence from Bangladesh remains limited, particularly regarding the relationship between caregiver knowledge, socioeconomic circumstances, and treatment practices among children with TDT. However, information from Bangladesh remains scarce. Understanding caregivers' knowledge and treatment practices may help identify areas where educational and support interventions are most needed.^{6,8,11,12}

Therefore, this study aimed to assess caregiver knowledge, treatment practices, and socioeconomic challenges among children with transfusion-dependent thalassemia attending a tertiary care hospital in Bangladesh, and to identify factors associated with blood transfusion adherence.

METHODS

Study design and setting

A hospital-based cross-sectional study was conducted in the Department of Pediatrics of the Institute of Child and Mother Health (ICMH), Dhaka, Bangladesh, from 1 July 2023 to 30 June 2025. ICMH is a tertiary referral and teaching hospital that provides specialized care for children with hematological disorders from different regions of the country.

Study participants

Children aged <18 years with hemoglobin electrophoresis-confirmed TDT (β -thalassemia major or HbE/ β -thalassemia) who attended the pediatric department for diagnosis, scheduled blood transfusion, or follow-up during the study period were eligible for inclusion. Consecutive eligible children were enrolled until the required sample size was achieved. Children whose primary caregivers declined to provide written informed consent were excluded.

Sample size

The sample size was calculated using the single population proportion formula. As no previous Bangladeshi study had reported the prevalence of adequate caregiver knowledge in a comparable population, a prevalence (P) of 50% was assumed to obtain the maximum sample size. Using a 95% confidence level ($Z=1.96$) and a margin of error of 10%, the minimum required sample size was 96 participants. To allow for incomplete data, the target sample size was increased to 100 caregiver-child pairs, all of whom were successfully enrolled.

Data collection

Data were collected through face-to-face interviews with the child's primary caregiver, who was usually the mother, using a pretested structured interviewer-administered questionnaire. The questionnaire was developed after reviewing the relevant literature and was pilot-tested before the commencement of the study to ensure clarity and feasibility. Interviews were conducted by the investigators after obtaining written informed consent.

Information collected included the child's age, sex, place of residence, thalassemia subtype, age at diagnosis, presenting clinical features, blood transfusion history, caregiver knowledge regarding thalassemia, treatment practices, and socioeconomic characteristics. Clinical information was verified from hospital records whenever available.

Study variables

The caregiver knowledge questionnaire was developed by the investigators after a comprehensive review of published literature, international thalassemia management guidelines, and previously published caregiver knowledge surveys. The initial questionnaire consisted of 30 multiple-choice items covering three domains: treatment modalities (10 items), nutritional management (10 items), and disease-related complications (10 items). The draft questionnaire was reviewed by three independent experts in pediatric hematology and pediatric medicine to assess its content relevance, clarity, and comprehensiveness. Minor

modifications were made based on their recommendations.

The revised questionnaire was pilot-tested among 10 caregivers of children with transfusion-dependent thalassemia who were not included in the final study to evaluate comprehensibility, wording, and administration time. Feedback from the pilot testing was used to refine the wording of several questions without changing their content. Each correct response was awarded one point, while incorrect or "don't know" responses received zero points, giving a total possible score of 30. Domain scores were categorized as good (8-10), partial (6-7), and poor (0-5). The final English version of the questionnaire is provided as supplementary appendix S1.

Caregiver awareness was assessed using questions on prior awareness of thalassemia, understanding of carrier status, and willingness to undergo family carrier screening. Socioeconomic characteristics included parental education, parental occupation, socioeconomic status, and the primary source of treatment financing.

The primary outcome variable was blood transfusion adherence, categorized as regular or irregular according to the child's transfusion history documented during the interview and verified from available hospital records. Blood transfusion adherence was selected as the dependent variable because regular transfusion is the cornerstone of treatment for transfusion-dependent thalassemia and is essential for preventing severe anemia, growth impairment, and disease-related complications. Furthermore, caregiver knowledge and socioeconomic circumstances are likely to influence adherence to scheduled transfusions; therefore, these variables were evaluated as potential predictors.

Statistical analysis

Data were entered, cleaned, and analyzed using IBM SPSS Statistics version 24.0 (IBM Corp., Armonk, NY, USA). Categorical variables were summarized as frequencies and percentages.

Blood transfusion adherence (regular vs. irregular) was considered the dependent variable. Independent variables included place of residence, parental educational attainment, parental occupation, socioeconomic status, caregiver knowledge, and other relevant demographic characteristics. Univariable analyses were performed initially to examine the association between each independent variable and blood transfusion adherence. Variables considered clinically relevant or demonstrating an association at $p < 0.20$ in the univariable analysis were entered into a multivariable binary logistic regression model to identify independent predictors of regular blood transfusion adherence. Adjusted odds ratios (aORs) with 95% confidence intervals (CIs) were reported. A two-sided $p < 0.05$ was considered statistically significant.

Ethical considerations

The study protocol was approved by the Institutional Review Board (IRB) of the ICMH, Dhaka, Bangladesh (Reference: ICMH/IRB-5MAY2023/01). Written informed consent was obtained from the primary caregiver of each participant before enrolment. All information collected during the study was kept confidential and used solely for research purposes.

RESULTS

One hundred caregiver-child pairs meeting the eligibility criteria were enrolled during the study period. More than half of the children (51%) were aged 1-5 years, 37% were older than 5 years, and 12% were younger than 1 year. There was a slight male predominance (53%). Nearly half of the participants resided in peri-urban areas (48%), followed by rural (35%) and urban (17%) areas. Most fathers (70%) had primary-level education or below, while 89% of mothers were homemakers. Consanguinity was reported in 5% of families (Table 1).

HbE/ β -thalassemia was the predominant subtype, accounting for 65% of cases, while β -thalassemia major comprised the remaining 35%. Half of the children were diagnosed before one year of age, and 42% received their diagnosis between 1 and 5 years of age. Pallor was the most common presenting feature (58%), followed by infection (36%), respiratory distress (28%), and failure to thrive (27%). More than three-fifths (61%) of the children had received over 20 lifetime BT. Regular blood transfusion adherence was observed in 56% of participants (Table 2).

Table 3 summarizes caregivers' knowledge regarding thalassemia across three domains: treatment modalities, nutrition, and complications. Overall, caregivers demonstrated limited knowledge, particularly regarding treatment modalities. Regarding treatment modalities, only 4% of caregivers had good knowledge, while 26% had partial knowledge and the majority (70%) had poor knowledge. Knowledge related to nutrition was comparatively better. Good knowledge was observed among 13% of caregivers, more than half (55%) demonstrated partial knowledge, and 32% had poor knowledge. For complications of thalassemia, 9% of caregivers had good knowledge, 49% had partial knowledge, and 42% had poor knowledge.

Caregiver awareness regarding thalassemia was limited. Before their child's diagnosis, 82% of caregivers had never heard of thalassemia, whereas only 12% had previous awareness of the disease. Although 61% were familiar with the concept of carrier status, 78% expressed willingness to undergo family carrier screening (Table 4).

Regarding socioeconomic characteristics, 40% of families belonged to the middle socioeconomic group, whereas 31% were from lower socioeconomic

backgrounds. Family members or neighbours were the principal source of blood donation for 76% of children. The most families (80%) financed treatment expenses from their own income, while 9 percent relied on loans and 8 percent resorted to begging to meet treatment-related costs (Table 5).

Multivariable logistic regression analysis identified paternal educational attainment below the primary level

as an independent factor associated with regular blood transfusion adherence (adjusted OR, 0.324; 95% CI, 0.128-0.817; $p=0.017$). No statistically significant associations were observed between blood transfusion adherence and place of residence, maternal educational attainment, paternal occupation, maternal occupation, or socioeconomic status (Table 6).

Table 1: Socio-demographic characteristics of children with thalassemia and their caregivers, (n=100).

Baseline characteristics	N (%)
Age of child (in years)	
<1	12 (12)
1-5	51 (51)
>5	37 (37)
Child sex	
Male	53 (53)
Female	47 (47)
Place of residence	
Urban	17 (17)
Peri-urban	48 (48)
Rural	35 (35)
Paternal educational attainment	
Below primary	34 (34)
Primary level completed	36 (36)
Secondary level completed	11 (11)
Higher secondary and above	19 (19)
Maternal educational attainment	
Below primary	25 (25)
Primary level completed	36 (36)
Secondary level completed	18 (18)
Higher secondary and above	21 (21)
Paternal occupation	
Service	14 (14)
Day laborer	37 (37)
Business	31 (31)
Others	18 (18)
Maternal occupation	
Service	3 (3)
Home maker	89 (89)
Garments worker	6 (6)
Others	2 (2)
State of consanguinity	
Consanguineous	5 (5)
Non-consanguineous	95 (95)

Table 2: Clinical profile and treatment characteristics of children with transfusion-dependent thalassemia, (n=100).

Clinical characteristics	N (%)
Type of transfusion-dependent thalassemia	
Thalassemia major	35 (35)
E-Beta thalassemia	65 (65)
Age at diagnosis (in years)	
<1	50 (50)
1-5	42 (42)
>5	8 (8)

Continued.

Clinical characteristics	N (%)
Presenting clinical feature*	
Pallor	58 (58)
Respiratory distress	28 (28)
Infection	36 (36)
Failure to thrive (FTT)	27 (27)
Others	18 (18)
Lifetime number of BT	
<5 times	13 (13)
5-20 times	26 (26)
>20 times	61 (61)
Blood transfusion adherence	
Regular	56 (56)
irregular	44 (44)

*Multiple responses permitted

Table 3: Caregiver knowledge regarding thalassemia, (n=100).

Knowledge domain	Good knowledge	Partial knowledge	Poor knowledge
Treatment modalities	4 (4%)	26 (26%)	70 (70%)
Nutrition	13 (13%)	55 (55%)	32 (32%)
Complications	9 (9%)	49 (49%)	42 (42%)

*Data are presented as number (percentage)

Table 4: Caregiver awareness regarding thalassemia, (n=100).

Knowledge parameter	N (%)
Prior awareness of thalassemia before diagnosis	
Yes, I heard the name before	12 (12)
Probably heard	6 (6)
No, never heard the name	82 (82)
Awareness of carrier status	
Yes, I know the term 'carrier'	61 (61)
No idea of 'carrier'	39 (39)
Willingness to undergo family carrier screening	
Yes, I'm willing to screen	78 (78)
Not sure	7 (7)
No, I'm not willing	15 (15)

*Data are presented as number (percentage).

Table 5: Financial and logistical challenges in thalassemia care, (n=100).

Financial issues	N (%)
Socio-economic status	
Upper	29 (29)
Middle	40 (40)
Lower	31 (31)
Source of blood donors	
Family members or neighbors	76 (76)
Self-donor	4 (4)
Commercial donor or blood bank	18 (18)
Others	2 (2)
Primary source of treatment financing (BT, medication, investigations, transport, etc.)	
Own income	80 (80)
Donation (Religious/ social)	3 (3)
Loan	9 (9)
Begging	8 (8)

Table 6: Factors associated with blood transfusion adherence, (n=100).

Factors	Adjusted OR	95% CI	P value
Peri-urban residence	0.796	0.338-1.873	0.601
Paternal education level (below primary)	0.324	0.128-0.817	0.017
Maternal education level (below primary)	1.579	0.650-3.838	0.313
Paternal occupation (day laborer)	1.305	0.697-2.442	0.406
Maternal occupation (home maker)	1.691	0.811-3.129	0.999
Low socio-economic status	1.708	0.708-4.110	0.232

*Multivariable logistic regression analysis was performed. $P < 0.05$ was considered statistically significant.

DISCUSSION

This study provides a comprehensive assessment of caregiver knowledge, treatment practices, and socioeconomic challenges among children with transfusion-dependent thalassemia attending a tertiary care hospital in Bangladesh. This study yielded several important findings. First, caregiver knowledge regarding thalassemia was generally inadequate despite a high willingness to undergo family carrier screening. Second, a substantial proportion of children experienced irregular BT despite requiring lifelong transfusion therapy. Third, the economic burden of treatment remained considerable, with many families relying on loans or other external support to sustain care. Finally, paternal educational attainment was independently associated with blood transfusion adherence.

Caregiver knowledge regarding thalassemia was suboptimal. More than four-fifths of caregivers had never heard of thalassemia before their child's diagnosis, and only a small minority demonstrated comprehensive knowledge of recommended treatment modalities, nutritional management, and disease-related complications. These findings are consistent with reports from Bangladesh and India, where inadequate awareness among caregivers has been identified as a major barrier to timely diagnosis, adherence to treatment, and disease prevention.^{8,12-14} Limited health literacy, insufficient public awareness campaigns, and restricted access to genetic counselling may explain these observations. These findings indicate that caregiver education at the time of diagnosis and during follow-up visits may improve understanding of the disease and encourage better treatment practices.

Despite poor baseline knowledge, more than three-quarters of caregivers expressed willingness to undergo family carrier screening. This finding suggests that acceptance of preventive strategies is high once families become aware of the hereditary nature of thalassemia. Similar observations have been reported from other South Asian countries, where education substantially increased the uptake of carrier screening and genetic counselling.¹⁵⁻¹⁷ Increasing public awareness and offering genetic counselling as part of routine thalassemia care may improve uptake of carrier screening in Bangladesh.

Regular BT remains the cornerstone of management for TDT.¹⁸ In the present study, only 56% of children received regular transfusions, while most had already undergone more than 20 lifetime transfusions, reflecting the chronic nature of the disease. Irregular transfusion practices may result from financial constraints, limited blood availability, travel distance to specialized centers, and competing family responsibilities. Similar barriers have been documented in other LMIC, where maintaining uninterrupted transfusion therapy remains challenging.^{6,19} Improving the availability of safe blood and reducing travel and financial barriers may help increase adherence to regular transfusions.

The study also highlights the substantial socioeconomic burden experienced by affected families. Although most caregivers financed treatment using their own income, a considerable proportion depended on loans or even begging to meet treatment-related expenses. Lifelong transfusion therapy, iron chelation, laboratory investigations, travel, and loss of work productivity collectively impose a significant financial burden on households. Comparable economic challenges have been described in previous studies from Bangladesh and neighboring countries.^{6,20,21} The financial burden observed in this study suggests that additional social and financial support may be required for families of children with transfusion-dependent thalassemia.

Paternal educational attainment was the only independent predictor of regular BT adherence. Fathers with higher educational attainment may better understand the importance of scheduled transfusions, recognize disease-related complications, and have greater ability to navigate healthcare services. Higher education is also frequently associated with improved health literacy and more effective health-seeking behavior.²² In contrast, place of residence, maternal education, parental occupation, and socioeconomic status were not independently associated with adherence after adjustment. The absence of significant associations for the remaining variables may be related to the relatively small sample size and the similar socioeconomic characteristics of many participating families. Larger multicenter studies are warranted to further explore the determinants of treatment adherence among children with thalassemia in Bangladesh.

The results of this study may help guide future caregiver education and thalassemia support programs in Bangladesh. Improving caregiver knowledge through structured education, strengthening genetic counselling and carrier screening programs, ensuring uninterrupted access to safe blood transfusion services, and reducing financial barriers to care may collectively improve treatment adherence and long-term outcomes among children with TDT. Such interventions are particularly relevant for resource-constrained settings where prevention and continuity of care remain major challenges.

Limitations

This study has several limitations. First, it was conducted at a single tertiary care hospital with a relatively small sample size, which may limit the generalizability of the findings to the wider population of children with transfusion-dependent thalassemia in Bangladesh. Second, the cross-sectional design precludes establishing causal relationships between caregiver characteristics and blood transfusion adherence. Third, caregiver knowledge and treatment practices were assessed using self-reported responses, which are subject to recall and social desirability bias. Finally, although blood transfusion adherence was verified from available hospital records whenever possible, information from children who received transfusions at other healthcare facilities may not have been completely captured. Nevertheless, the study provides baseline information on caregiver knowledge and treatment practices among children with transfusion-dependent thalassemia in a tertiary hospital in Bangladesh.

CONCLUSION

Caregiver knowledge regarding TDT is inadequate, yet willingness for family carrier screening remains high. Lifelong treatment creates severe financial strain, resulting in only half of the children receiving regular BT. Higher paternal education independently drives transfusion adherence. To improve long-term outcomes, interventions must urgently target caregiver education, expand genetic counseling, and eliminate financial barriers to ensure consistent access to transfusion services.

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