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Depression, anxiety, and stress among mothers of children with thalassemia in Bangladesh: a cross-sectional study

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Abstract

Background Despite Bangladesh being one of the major hotspots of thalassemia in the world, this preventable inherited blood disorder is neglected in research and policy level. Mothers are the primary caregivers of children in South Asian countries with limited resources. Caring for a child with thalassemia can be an emotionally challenging experience for mothers in low and middle-income countries including Bangladesh. This study aimed to explore the levels of depression, anxiety, and stress of the mothers of thalassemic patients in Bangladesh and to correlate with sociodemographic and thalassemia-related factors.

Methods This cross-sectional study, conducted with 156 mothers of children with thalassemia, was a continuation of a previous investigation conducted at Bangladesh Thalassaemia Samity Hospital (BTSH) regarding the parental perspective of thalassemia in Bangladesh. A validated Bengali version of the DASS-21 questionnaire was employed to assess the depression, anxiety, and stress levels of mothers with thalassemic children. Descriptive statistics were used to examine sociodemographic characteristics, thalassemia concerns in the family, effects on social and professional life, and DASS-21 scores. The depression, anxiety, and stress levels were predicted using a multiple-regression model.

Results We found that most mothers of thalassemia children experienced stress (~62%), anxiety (~58%), or depression (~63%) to some extent. Mental health concerns were significantly associated with education level ($p < 0.01$ for depression and stress and $p < 0.05$ for anxiety), spouse's education level ($p < 0.01$ for depression, anxiety and stress), monthly family income ($p < 0.01$ for depression and stress and $p < 0.05$ for anxiety), mortality from thalassemia in the extended family ($p < 0.01$ for depression and $p < 0.05$ for anxiety and stress), years of suffering ($p < 0.10$ for depression and anxiety), frequency of transfusions ($p < 0.10$ for depression and $p < 0.05$ for anxiety), social life ($p < 0.01$ for depression, anxiety and stress), and worry about the child's future ($p < 0.05$ for depression and $p < 0.01$ for stress). Depression and anxiety were significantly influenced by the frequency of transfusions as well as monthly cost of treatment. Multiple linear regression analysis showed that the likelihood of lower level of depression among mothers was associated with higher family income (95% CI [-0.48, -4.67]) and children who had more than a 30-day gap between two transfusions. On the other hand, the likelihood of a higher level of depression was associated with a higher monthly treatment cost (95% CI [-0.48, -4.67], $p = 0.037$).

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Conclusions Mothers of thalassemic patients in Bangladesh experience complex mental health challenges, including stress, anxiety, and depression. The chronic nature of the condition, combined with associated financial, social, and physical burdens, can lead to heightened levels of these mental health issues. This study provides insights for social organizations and policymakers to adopt a holistic approach in improving the overall mental well-being of mothers with thalassemic children in Bangladesh.

Keywords Thalassemia, Bangladesh, Mental health, Primary caregiver, Chronic disease

Background

Thalassemia, an inherited blood disorder, is a significant public health concern in the present world. In the past, only certain regions of the world such as the Mediterranean, Southeast Asia, and the Middle East used to be considered the endemic zone for thalassemia. However, due to migration and globalization, the prevalence of thalassemia is increasing in the regions where it was lower previously [1, 2]. Approximately 56 thousand children are born with thalassemia disease every year in the world [3]. According to the latest estimates, the age-standardized prevalence rates (ASPR) for thalassemia was 18.28 per 100,000 people worldwide in 2021 [4]. The World Health Organisation (WHO) has included thalassemia in its estimate of the worldwide burden of illness and has classed it as a major global health problem.

Thalassemia is caused by a defect in the gene that codes the globin protein of the haemoglobin molecule of the red blood cells. As a result, the abnormal or inadequate production of haemoglobin occurs which impedes the physiologic functions of the red blood cells such as the transportation of oxygen to the cells. To restore the functions of red blood cells, thalassemia patients need a regular blood transfusion. It is not affordable and accessible for most people in lower and middle-income countries [5, 6].

To ensure a secure blood transfusion, a series of screening tests and procedures are necessary, even after collecting fresh blood. These measures are essential to reduce the potential transmission of hepatitis B and C viruses, human immunodeficiency virus, and, in many nations, malaria parasites to the recipient. Continuous blood transfusions lead to the gradual buildup of excess iron in the body's tissues. To restore the body's normal iron levels, a costly treatment known as iron-chelating therapy is required [7]. As a result, thalassemia patients need to visit the hospital to seek medical attention at least once a month associated with a long-term burden of regular availability of an appropriate group of blood, cost of diagnostic technology, cost and availability of medicines, unexperienced medical staff, hospital admissions, and some other unavoidable items that are difficult to define [8].

Although Bangladesh is a lower-middle-income and small country, it is densely populated having over 170 million population [9]. Approximately, 60,000–70,000 thalassemia patients are suffering from thalassemia and there are about 10–19 million carriers of thalassemia in Bangladesh [10]. A study from Bangladesh at Thalassemia Foundation Hospital between 2009 and 2014 showed that a total of 1594 thalassemia patients were attended over five years. Moreover, approximately 91% of the patients required blood transfusion and 66.9% of them were TDT patients [8]. According to the existing carrier frequency of thalassemia, it can be estimated that 9,100 babies are born with thalassemia each year in Bangladesh [2]. These large numbers of thalassemia patients have to go through a costly treatment procedure for their whole life. It not only affects the patients themselves but also burdens their families both economically and emotionally.

In Bangladesh, the parents, especially the mothers, are assumed to play the most important role in caring for a thalassemic child who requires ongoing care [11, 12]. The mental health and quality of life of the mothers of thalassemia children have always been of interest to researchers. Psychological distress is one of the most important sufferings of the mothers of children with thalassemia [13]. The existence of chronic or life-threatening illnesses in children can stress out mothers and put them at risk of depression disorders. A study from Iran found that mothers of thalassemic children had significantly higher depression than mothers in the control group [14]. Regarding the mental health of the mothers with thalassemic children in Bangladesh, Mohiuddin et al. (2020) studied only the parenting stress and found that the majority of the mothers faced moderate level of stress [15].

This study can be the first step to unravelling the concerns of multidimensional mental health issues such as depression, anxiety, and stress of the mothers of thalassemic patients in Bangladesh as well as the sociodemographic and thalassemia-related factors associated with these concerns. The mothers are the ones on whom the quality of the lives of the patients is dependent. Early detection of anxiety, stress, and depression can help in both preventing serious deterioration and accelerating early recovery. So, this study can assist social organizations as well as policymakers to initiate a holistic approach in order to improve the overall mental well-being of the mothers of thalassemic children in Bangladesh.

Methods

Study setting and participants

This cross-section study was a continuation of a previous study conducted at Bangladesh Thalassaemia Samity Hospital (BTSH) about the parental perspective of thalassemia in Bangladesh [16]. A total of 365 parents (mother or father) of thalassemia patients attending BTSH for follow-up treatment during the whole year of 2018 participated in that study. BTSH is one of the few specialized thalassemia care centers in Bangladesh, located in the capital city of Dhaka, that has around 4,000 registered patients all over the country. This study conveniently enrolled mothers of those 365 patients from the first round and successfully collected data from 156 mothers. The inclusion criteria for the study were: participating in the first round of data collection, being the mother of the affected patient, being reachable through telephone calls, and being interested to participate. The exclusion criteria were: being mentally and physically unstable to communicate and the mother or the concerned patient being dead in the meantime.

Questionnaire and data collection

For socio-demographic information, the previously published structured questionnaire was used [16]. The socio-demographic section of the questionnaire included information about the mother (such as age, sex, monthly income, education, occupation, family size, and number of thalassemic children). Questions related to thalassemia included the number of years of suffering from thalassemia, transfusion frequency, treatment cost, and history of thalassemia (existence of any patient and death due to thalassemia) among relatives. Four Likert scale questions were added to assess the effect of thalassemia on social and professional life, these are about relationship with husband, social life activities, worry about the future and impact on career.

The second part of the questionnaire is the DASS-21 questionnaire. This self-report scale to measure the state of depression, anxiety and stress includes 7 items from each of the 3 subscales [17]. DASS is a reliable and valid method of assessing features of depression, anxiety, and stress in both clinical and nonclinical groups [18]. The DASS-21 is the shortened version of DASS-42. The 21-item version has several advantages like fewer questions, a clearer factor structure, and lower interfactor correlations. The Bangla translation of the DASS-21 questionnaire was validated [19].

Data were collected through telephone interviews by five female well-trained enumerators (a thalassemia patient, a wife of a thalassemia patient and medical student, a pharmacist, and a biomedical engineer). It took around 20 to 30 min for each interview. Among the 365 cases from the first-round, 4 cases were duplicated. Therefore, out of 361 unique cases, 136 were unreachable through phone calls. Changing contact numbers frequently, using multiple SIM cards, and inactivity of old SIM cards were common phenomena in the context of Bangladesh. Also, there were some invalid entries of phone numbers in the first round of the survey. Therefore, it was difficult to track all cases after two years of the first round. Among the 225 cases that we could reach, 168 mothers were interested in participating (the major causes of not-interested cases are the illness of the mother or the mother living in another place). During these two years, 6 patients and 4 mothers were died. Five cases remained incomplete due to various reasons (being busy or not understanding the local language). So, we could complete data collection from only 153 mothers from the first round. Before starting the survey, the questionnaire was piloted among 3 mothers of children with thalassemia to check the issues and feasibility of data collection. As the data collection went smoothly during piloting and no issues were reported, the questionnaire did not need any revision. This allowed us to include these 3 pilot observations in our original sample. Adding these 3 cases from the pilot, the second-round cases became 156 in total (Fig. 1).

Depression, anxiety, stress scoring

Each of the three DASS-21 scales (depression, anxiety, and stress) contains 7 items. Each item had a rating scale of 0 to 3 (0 means "Did not apply to me at all", 1 means "Applied to me to some degree, or some of the time", 2 means "Applied to me to a considerable degree or a good part of time", and 3 means "Applied to me very much or most of the time"). The DASS-21 scores were multiplied by 2 to calculate the final scores of depression, anxiety, and stress [17]. Therefore, for each scale, the minimum score was 0 and the maximum score was 42. Each scale was defined with five severity levels- normal, mild, moderate, severe, and extremely severe. A higher score on DASS should alert to a higher level of depression, anxiety, and stress respectively [20].

Large sample data that is non-normal can be identified by skewness values greater than 2 and kurtosis values greater than 7 [21]. With skewness values less than 1 and kurtosis values around 2 in all of the scales, we can conclude that each of the scales was normally distributed. We also tested the internal consistency of the items in each of the scales using Cronbach's alpha. We found alpha between 0.855 and 0.862 for depression, anxiety, and stress suggesting reliable internal consistency of each of the scales.

Data management and statistical analysis

A dedicated Google sheet was used for real-time tracking of data collection progress. The REDCap (Research

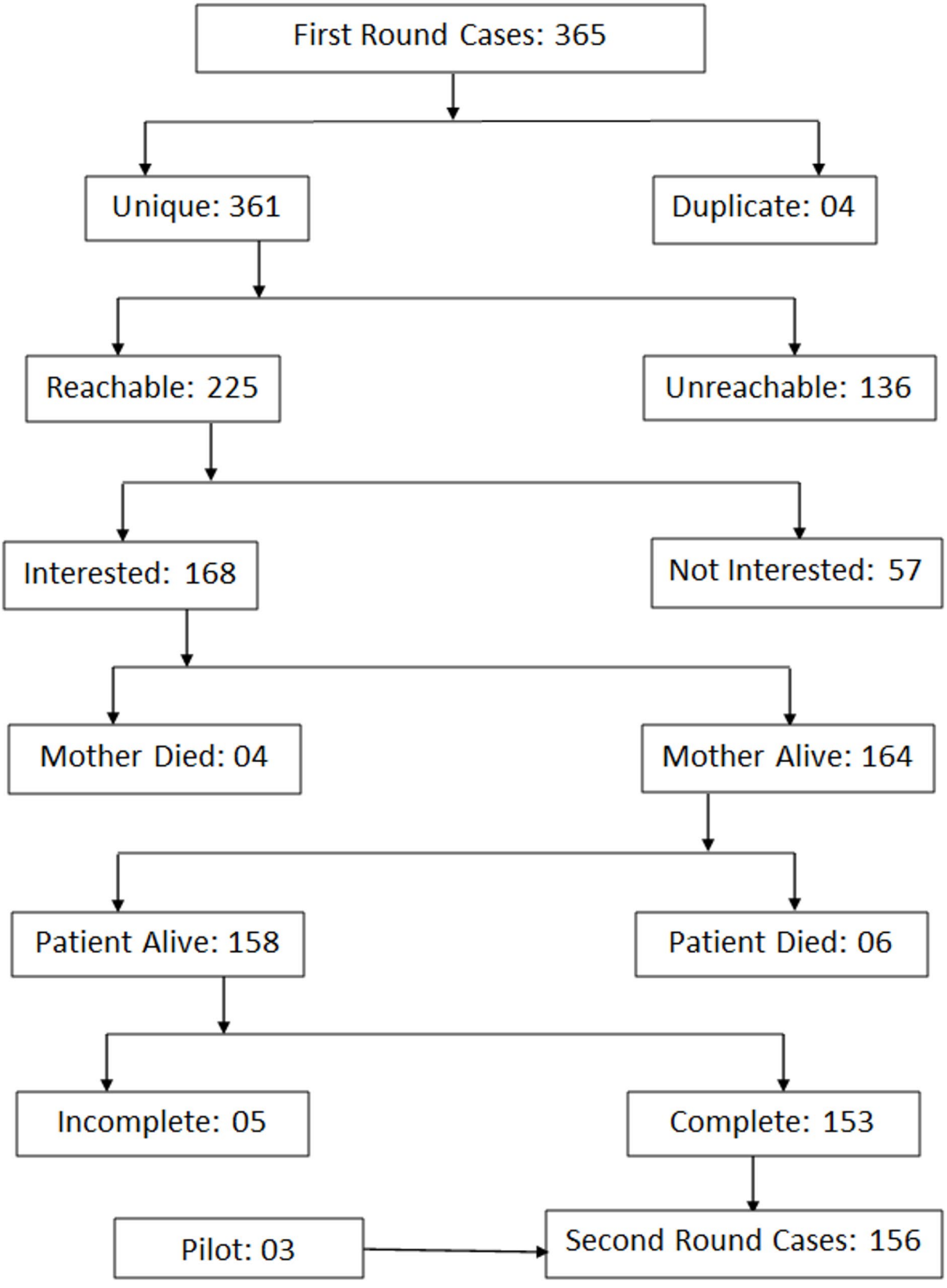

Fig. 1 Data collection flow chart

Table 1 Demographic characteristics

Variable	*n*	%
Age of Mother (in full years)		
Mean (SD)	40.38 (8.89)	
Marriage Type		
Arranged	130	83.33
Affair	26	16.67
Highest Education of Father		
Illiterate	9	5.77
Primary	36	23.08
Secondary	18	11.54
Higher Secondary	31	19.87
Graduate	62	39.74
Highest Education of Mother		
Illiterate	9	5.77
Primary	45	28.85
Secondary	33	21.15
Higher Secondary	33	21.15
Graduate	36	23.08
Monthly Family Income (BDT)		
< 15,000	54	34.62
15,000–24,999	49	31.41
25,000–49,999	32	20.51
>= 50,000	21	13.46
Number of children		
1	32	20.51
2	81	51.92
3 or more	43	27.56
Family Size		
1–3	33	21.71
4–5	100	65.79
6 or more	19	12.50

Electronic Data Capture) System received the collected data and processed them. Stata version 13 was used to analyze the data that was exported from REDCap. Using descriptive statistics, the sociodemographic characteristics, thalassemia concerns in the family, effects on social and professional life, and DASS-21 score were examined. The mean difference of the DASS-21 scores between or among the categories of demographic, thalassemia-related, and social issues was calculated using the t-test and ANOVA statistics. The depression, anxiety, and stress levels were predicted using a multiple-regression model. The fraction of missing values was too little to have a major impact on the outcomes.

Ethical approval

The study protocol was approved by the institutional review board of the Biomedical Research Foundation, Bangladesh (Ref. no: BRF/ERB/2029/001). Written informed consent was taken from each participating mother in the first phase of the study. During follow-up study, verbal consent was taken from each participant during the telephone interview.

Table 2 Thalassemia issues in family

Variable	*n*	%
Number of thalassemic children		
1	129	82.69
More than 1 (2 or 3)	27	17.31
Any other thalassemia patients in extended family and relatives		
Yes	34	22.97
No	114	77.03
Any death due to thalassemia in extended family and relatives		
Yes	28	18.67
No	122	81.33
Number of years the 1st thalassemic child has been suffering from thalassemia		
0–5	6	3.85
6–10	35	22.44
11–15	47	30.13
16–20	36	23.08
21–25	22	14.10
> 25	10	6.41
Transfusion Frequency		
<= 15 days	50	32.47
16–30 days	91	59.09
> 30 days	13	8.44
Monthly Cost of Treatment (BDT)		
<=5,000	38	24.84
5,001–10,000	71	46.41
10,001–20,000	37	24.18
20,001–30,000	5	3.27
> 30,000	2	1.31

Results

The average age of the participating mothers is around 40.38 years (SD ± 8.89). Most of the fathers and mothers of thalassemia patients have graduated (39.74% and 23.08%, respectively). Family income falls below 15,000 BDT (~ US$174) for the majority of patients (34.62%). (Table 1).

A significant proportion (17.31%) of the participating mothers had more than one child affected by thalassemia. Approximately 22.97% of them reported other cases of thalassemia within their extended family, while 18.67% had experienced the tragic loss of a family member due to this condition. The majority of families in this study have been living with thalassemia for 11–15 years. More than half of these patients require regular blood transfusions every 16–30 days (59.09%). It is noteworthy that the monthly cost of thalassemia treatment falls in the range of 5,000 to 10,000 BDT (~ US$58–116) for the majority of cases (46.41%) (Table 2).

Around 22.44% of mothers had an unpleasant relationship with their husbands, with 9.62% agreeing and 12.82% strongly agreeing. A significant portion of mothers, 46.79%, felt (agree or strongly agree) that their family's social life was hampered. Concerns about their child's future were prevalent in the majority of families.

Table 3 Social and professional life

Statement	Strongly Disagree *n* (%)	Disagree *n* (%)	Neutral *n* (%)	Agree *n* (%)	Strongly Agree *n* (%)
I have an unpleasant relationship with my husband	78 (50)	26 (16.67)	17 (10.9)	15 (9.62)	20 (12.82)
Our social life is hampered (less participation in social activities, weak bond with relatives)	37 (23.72)	31 (19.87)	15 (9.62)	40 (25.64)	33 (21.15)
We are concerned about our child's future (education/ job/ marriage/ pregnancy)	4 (2.56)	5 (3.21)	6 (3.85)	43 (27.56)	98 (62.82)
My long-term professional career goal is hampered because of my child's chronic condition	57 (36.54)	26 (16.67)	8 (5.13)	35 (22.44)	30 (19.23)

Table 4 Depression, anxiety, and stress level

Descriptive statistics	Depression	Anxiety	Stress
Severity levels, n (%)			
Normal	57 (37.01)	65 (41.67)	58 (38.16)
Mild	13 (8.44)	9 (5.77)	16 (10.53)
Moderate	40 (25.97)	29 (18.59)	22 (14.47)
Severe	20 (12.99)	15 (9.62)	39 (25.66)
Extremely Severe	24 (15.58)	38 (24.36)	17 (11.18)
Mean (SD)	14.51 (10.89)	11.46 (10.07)	19.43 (10.74)

Additionally, 41.67% of mothers reported that their long-term professional career goals were hampered (Table 3).

Regarding depression, 8% of mothers had mild depression, 25.97% had moderate, 12.99% had severe, and 15.58% experienced an extremely severe level of depression, others being within the normal range. In terms of anxiety, 5.77% of mothers had mild anxiety, 18.59% had moderate, 9.62% had severe, and 24.36% experienced an extremely severe level of anxiety, with remaining in the normal range. For stress, 10.53% of mothers reported mild stress, 14.47% had moderate, 25.66% had severe, 11.18% experienced an extremely severe level of stress. We found the mean depression, anxiety, and stress scores of 14.51 (±10.89), 11.46 (±10.07), and 19.43 (±10.74) respectively among the studied mothers (Table 4).

Table 5 reports the levels of depression, anxiety and stress in comparison with demographic variables. Mothers in arranged marriages had lower anxiety scores (10.8) compared to those with affair marriages (14.77) ($p = 0.067$). Mothers whose husbands were graduates had significantly lower depression scores (10.42) than those with illiterate husbands (26) or primary pass (17.77) ($p = 0.0001$). Similarly, mothers with a graduation had significantly lower depression scores (8) compared to illiterate (21.11) and primary pass (18.51) ($p = 0.0001$).

Families with a monthly income above 50,000 BDT (~US$581) had significantly lower mean depression scores for mothers (6.86) compared to those with incomes less than 15,000 (18.98) or between 15,000 and 24,999 BDT (~US$174–291) (15.13) ($p = 0.0000$). Families with incomes between 25,000 and 49,999 BDT (~US$291–581) (11.19) also had significantly lower depression scores compared to those with incomes less than 15,000 BDT (~US$174) (18.98). A similar pattern was observed for anxiety and stress scores concerning the spouse's education, mother's education, and family income. It's worth noting that the age of the mother, number of children, and family size did not show significant associations with any of the scores.

Mothers with more than one thalassemic child (14.96) had significantly higher mean anxiety scores ($p = 0.047$) than those having one thalassemic child (10.73). Any death due to thalassemia in the extended family and state of social life are significantly associated with depression, anxiety and stress scores. Concern about the child's future is significantly associated with stress score while transfusion frequency and number of years of suffering with thalassemia are significantly associated with depression and anxiety. The existence of any thalassemia patient in the extended family, monthly cost of treatment, and relationship with spouse have no significant association with the mother's depression, anxiety and stress score (Table 6).

The results of multiple linear regressions to identify the significant factors associated with depression, anxiety and stress are presented in Table 7. Mothers having a monthly family income of more than 50,000 BDT (~US$581) had a (mean 7.79-score) lower depression (95% CI [-0.48, -4.67], $p = 0.037$) compared to those with less than 15,000 BDT (~US$174) monthly family income; other variables held constant. A similar result was found in terms of stress. Mothers with 6 or more members in the household had a significantly (mean 6.41-score) higher stress than those with 1 to 3 members (95% CI [-0.56, 13.37], $p = 0.071$), other variables held constant.

Mothers whose thalassemic children had more than 30 days gap between two transfusion days had a significantly (mean 6.07-score) lower depression than the mothers of those with less than 15 days gap (95% CI [-12.37, 0.24], $p = 0.059$); other variables held constant. A similar result is found in terms of anxiety. Mothers who faced a cost of more than 30,000 BDT (~US$349) to treat their thalassemic children each month had a significantly (mean 22.44-score) higher depression than those who spend less than or equal to 5,000 BDT (~US$58) per month (95% CI [-0.48, -4.67], $p = 0.037$); other variables held constant. Similar results are found in the case of anxiety and stress.

Table 5 Comparison of depression, anxiety, and stress in mothers based on demographic variables

Variables	Depression		Anxiety		Stress	
	Mean	*P*-value	Mean	*P*-value	Mean	*P*-value
Age of Mother (Years)						
<=30	15.22	0.736	11.22	0.9	21.36	0.364
> 30	14.38		11.5		19.11	
Marriage Type						
Arranged	14.28	0.571	10.8	0.067*	19.06	0.351
Affair	15.62		14.77		21.23	
Highest Education of Father						
Illiterate	26	0.0001***	20.22	0.0003***	28.89	0.0002***
Primary	17.77		15		23.43	
Secondary	15.44		12.89		20.78	
Higher Secondary	15.23		11.48		19.2	
Graduate	10.42		7.71		15.4	
Highest Education of Mother						
Illiterate	21.11	0.0001***	17.33	0.0223**	22.22	0.0022***
Primary	18.51		13.47		22.84	
SSC	14.85		12.91		21.39	
HSC	14.24		9.58		18.18	
Graduate	8		7.89		13.71	
Monthly Family Income						
< 15,000	18.98	0.0000***	14.07	0.0196**	23.04	0.0023***
15,000–24,999	15.13		11.51		18.98	
25,000–49,999	11.19		10.44		18.45	
>=50,000	6.86		6.19		12.7	
Number of children						
1	14	0.9468	9.56	0.4703	18	0.6727
2 or 3	14.52		12.15		19.56	
> 3	14.86		11.58		20.23	
Family Size						
1–3	14.5	0.7126	10.06	0.2421	18.06	0.1821
4–5	14.38		11.58		19.42	
>=6	16.63		14.95		23.68	

* $P < 0.1$; ** $P < 0.05$; *** $P < 0.01$

Checked all ANOVA using Bartlett's test for equal variances, all the p-values are insignificant

Those mothers who were neutral or agreed to the fact that their social life was hampered had a higher anxiety than the mothers who strongly disagreed; holding other variables constant. Similarly, those mothers who strongly agreed to the fact that they were concerned about their child's future had a higher stress than the mothers who strongly disagreed.

The model summary for depression, anxiety, and stress (adjusted $R^2 = 0.14$, 0.08, 0.14, respectively) suggests that the selected predictors can explain about 14%, 8%, and 14 variations of the overall depression, anxiety, and stress respectively.

Discussion

This study, for the first time, investigated the mental health concerns of mothers with thalassemic children in Bangladesh setting, specifically focusing on depression, anxiety, and stress. The research identified various factors associated with these concerns, including education level, monthly family income, death in the extended family due to thalassemia, duration of suffering, transfusion frequency, social life, and worry for the future. Based on the data from 156 mothers having children with thalassemia, the findings revealed that mothers with thalassemic children commonly experience depression, anxiety, or stress. Factors such as higher treatment costs and increased transfusion frequency were linked to elevated levels of depression, anxiety, and stress. The challenges of managing blood/donors and the financial burden further contribute to the difficulty of coping with the disease, impacting the mental health of the mothers. Solvent family backgrounds were associated with lower depression and stress levels, while larger family sizes correlated with increased stress. Additionally, social life and concerns about the child's future were identified as significant determinants of anxiety and stress, respectively.

Table 6 Comparison of depression, anxiety, and stress in mothers based on thalassemia issues and social life

Variables	Depression		Anxiety		Stress	
	Mean	*P*-value	Mean	*P*-value	Mean	*P*-value
Number of thalassemic children						
1	13.91	0.138	10.73	0.047**	18.92	0.196
More than 1	17.33		14.96		21.92	
Any other thalassemia patients in extended family						
Yes	15.94	0.413	11.77	0.834	20.24	0.687
No	14.16		11.35		19.39	
Any death due to thalassemia in extended family						
Yes	20.45	0.003***	15.22	0.037**	23.93	0.02**
No	13.45		10.8		18.66	
Number of years the 1st child has been suffering from thalassemia						
0–5	16.67	0.0942*	14.33	0.0823*	26.33	0.3239
6–10	12.86		9.09		17.94	
11–15	12.55		10.51		18.53	
16–20	18.63		15.67		21.83	
21–25	12.48		10		17.62	
> 25	18		10.6		19.6	
Transfusion Frequency						
<= 15 days	17.35	0.0693*	14.12	0.0473**	21.15	0.1910
16–30 days	13.44		10.46		19.29	
> 30 days	11.23		7.85		15.08	
Monthly Cost of Treatment						
<=5,000	16.42	0.4841	12.74	0.3543	20.54	0.39
5,001–10,000	13.94		10.31		19.01	
10,001–20,000	14.27		13.24		20.06	
20,001–30,000	8		6		14.8	
> 30,000	19		15		21	
I have an unpleasant relationship with my husband						
Strongly Disagree	13.95	0.2793	10.26	0.1333	18.03	0.2235
Disagree	12.16		9.92		18.62	
Neutral	14.13		11.53		19.63	
Agree	15.6		14.13		23.14	
Strongly Agree	19.1		16.1		23.37	
Our social life is hampered (less participation in social activities, weak bond with relatives)						
Strongly Disagree	10.97	0.0063***	6.7	0.0068*** (#)	15.08	0.0021***
Disagree	12.77		10.97		17.67	
Neutral	13.57		11.87		18.13	
Agree	14.72		13.05		20.95	
Strongly Agree	20.24		15.15		24.94	
We are concerned about our child's future (education/job/marriage/pregnancy)						
Strongly Disagree	7.5	0.0445**	9	0.1485	11.5	0.0009***
Disagree	4		2		6.8	
Neutral	7.67		6.33		8.33	
Agree	15		12.14		19.3	
Strongly Agree	15.55		11.46		21.16	

* $P < 0.1$; ** $P < 0.05$; *** $P < 0.01$

Checked all ANOVA using Bartlett's test for equal variances, all the p-values are insignificant except #

Our study found mild to extremely severe levels of depression among almost two-thirds of the studied mothers of thalassemia patients (~63%), anxiety among more than half of the mothers (~58%), and stress among three-fifths (~62%) of the mothers. These proportions are significantly higher compared to that of Bangladeshi adults from urban areas on average having mild to severe levels of depression (32%), anxiety (47%), and stress (42.50%) [22]. In our study, most mothers of thalassemic children experience varying levels of depression, anxiety,

Table 7 Multiple regression model predicting depression, anxiety, stress

Characteristics	Depression score				Anxiety score				Stress scores			
	Coef.	*p*-value	[95% CI]		Coef.	*p*-value	[95% CI]		Coef.	*p*-value	[95% CI]	
			LB	UB			LB	UB			LB	UB
Age	0.059	0.734	−0.284	0.402	−0.143	0.433	−0.503	0.217	−0.068	0.666	−0.382	0.245
Highest education of mother (Ref: Illiterate)												
Primary	0.507	0.933	-11.462	12.476	-1.592	0.751	-11.537	8.352	2.936	0.499	-5.638	11.51
Secondary	−0.408	0.947	-12.566	11.751	−0.123	0.983	-11.254	11.008	3.791	0.426	-5.609	13.191
Higher Secondary	−0.739	0.905	-12.934	11.457	-4.695	0.384	-15.335	5.946	0.319	0.945	-8.862	9.5
Graduate	-4.646	0.489	-17.928	8.636	-2.309	0.705	-14.376	9.758	0.045	0.993	-9.793	9.882
Monthly family income (Ref: <15,000 BDT)												
15,000–24,999	-3.47	0.211	-8.937	1.997	-2.624	0.281	-7.425	2.178	-4.371	0.095*	-9.509	0.768
25,000–49,999	-6.793	0.058*	-13.818	0.232	-3.457	0.273	-9.673	2.758	-2.396	0.455	-8.736	3.945
> 50,000	-7.787	0.037**	-15.096	−0.479	-4.672	0.154	-11.129	1.785	-6.505	0.089*	-14.011	1.002
Family Size (Ref: 1–3)												
4–5	-1.778	0.53	-7.37	3.815	1.554	0.55	-3.585	6.693	2.433	0.321	-2.407	7.273
6 or more	−0.03	0.994	-7.502	7.442	5.319	0.126	-1.524	12.162	6.406	0.071*	−0.557	13.369
Thalassemia patient in extended family (Ref: No)												
Yes	0.685	0.786	-4.292	5.662	−0.949	0.716	-6.106	4.208	-1.122	0.637	-5.828	3.584
Death due to thalassemia in extended family (Ref: No)												
Yes	3.213	0.301	-2.919	9.346	3.466	0.169	-1.5	8.432	2.82	0.292	-2.462	8.102
Number of years the 1st child has been suffering from thalassemia	0.146	0.537	−0.321	0.612	0.192	0.355	−0.219	0.604	0.062	0.782	−0.383	0.508
Transfusion frequency (gap between transfusion days) (Ref: <15 = days)												
16–30 days	-1.694	0.427	-5.911	2.523	-1.887	0.378	-6.112	2.337	−0.179	0.932	-4.341	3.983
> 30 days	-6.067	0.059*	-12.374	0.239	-5.466	0.097*	-11.938	1.006	-4.256	0.247	-11.511	3
Monthly treatment cost (Ref: <=5,000 BDT)												
5,001–10,000	2.524	0.369	-3.028	8.076	−0.218	0.931	-5.175	4.739	1.641	0.532	-3.545	6.827
10,001–20,000	0.681	0.845	-6.204	7.566	1.825	0.559	-4.347	7.998	1.333	0.682	-5.096	7.762
20,001–30,000	-5.061	0.254	-13.815	3.693	-5.232	0.23	-13.833	3.369	-3.292	0.556	-14.338	7.755
> 30,000	22.435	0***	10.419	34.45	17.136	0.002***	6.311	27.961	20.296	0.077*	-2.22	42.812
I have an unpleasant relationship with my husband (Ref: Strongly Disagree)												
Disagree	-1.413	0.597	-6.694	3.867	-1.516	0.624	-7.629	4.597	0.044	0.987	-5.252	5.341
Neutral	-4.145	0.214	-10.725	2.435	-1.059	0.739	-7.347	5.229	-1.302	0.682	-7.597	4.993
Agree	-1.755	0.667	-9.816	6.305	−0.387	0.901	-6.567	5.792	0.028	0.994	-7.249	7.306
Strongly Agree	3.517	0.294	-3.097	10.131	2.441	0.43	-3.664	8.546	2.299	0.46	-3.85	8.448
Our social life is hampered (Ref: Strongly Disagree)												
Disagree	2.06	0.541	-4.593	8.713	4.808	0.119	-1.258	10.873	1.819	0.541	-4.06	7.698
Neutral	1.852	0.612	-5.362	9.066	5.249	0.08*	−0.629	11.128	0.603	0.877	-7.086	8.293
Agree	1.334	0.641	-4.321	6.988	4.226	0.084*	−0.574	9.025	2.401	0.396	-3.191	7.992
Strongly Agree	4.071	0.247	-2.865	11.007	3.628	0.163	-1.496	8.752	4.041	0.182	-1.918	9.999
We are concerned about our child's future (Ref: Strongly Disagree)												

Table 7 (continued)

Characteristics	Depression score				Anxiety score				Stress scores			
	Coef.	*p*-value	[95% CI]		Coef.	*p*-value	[95% CI]		Coef.	*p*-value	[95% CI]	
			LB	UB			LB	UB			LB	UB
Disagree	1.042	0.872	-11.761	13.845	-1.783	0.837	-18.9	15.335	1.914	0.817	-14.484	18.311
Neutral	-1.286	0.869	-16.662	14.091	-2.462	0.783	-20.186	15.261	-2.057	0.782	-16.732	12.618
Agree	5.143	0.362	-6.004	16.29	1.975	0.808	-14.095	18.045	8.627	0.147	-3.082	20.337
Strongly Agree	5.285	0.355	-6	16.57	1.169	0.889	-15.429	17.768	10.226	0.076*	-1.088	21.539
Constant	9.301	0.391	-12.121	30.724	13.553	0.275	-10.947	38.054	8.521	0.379	-10.607	27.649
Model Summary												
Model F									F (31, 101) = 1.68 Prob > F = 0.0281			
R^2	0.3407				0.2889				0.3403			
Adjusted R^2	0.1403				0.0769				0.1378			

* $P < 0.1$; ** $P < 0.05$; *** $P < 0.01$

CI = Confidence Interval; LB = Lower Bound; UB = Upper Bound

or stress. This aligns with findings from similar studies in India, Indonesia, Pakistan, and Iran, where a majority of parents caring for thalassemia patients reported experiencing stress, mental burden, depressive symptoms, and overall poor mental health [12, 23–25].

Our study found that the cost of treatment and frequency of blood transfusions are significant determinants of mental health where higher treatment cost and higher transfusion frequency are responsible for worse mental health status. This gives a justification of why the studied mothers have lower mental health status compared to the urban Bangladeshi adults in general. This re-emphasizes the significance of the child's disease translating into the mother's mental health problem, as found by Sarghi et al. (2006) [14].

In our study, we uncovered some noteworthy insights. While a minority of mothers reported experiencing discord in their relationships with their spouses, the majority expressed a consensus regarding the impact on their social lives. Furthermore, nearly all the mothers in our study shared deep concerns regarding their thalassemic child's future, encompassing their education, career prospects, and prospects for a fulfilling conjugal life. These findings resonate with prior research conducted in Pakistan, where the cultural context mirrors our observations [24, 26]. They found that parents of thalassemic patients often face challenges in their social interactions and express concerns about their children. However, their cultural context appears to preserve their relationships with their spouses, despite the challenges posed by the disease [26]. This pattern aligns with the findings of another study in Pakistan, where a substantial number of parents encountered disapproval from their relatives (56%), yet their spousal relationships remained unaffected (77%) [24]. Notably, a significant portion of mothers in our study acknowledged that their long-term professional aspirations were hindered. This is a noteworthy observation given that a substantial percentage of these mothers had completed higher secondary education (~21%) or even obtained a bachelor's degree (~23%).

Education and family income are significant determinants of depression and stress among women in general [27]. In our investigation, we identified a substantial connection between the educational background and family income of the mothers under study and their mental health status. Notably, mothers with higher levels of education displayed significantly lower depression, anxiety, and stress on average. Additionally, a higher family income was linked to improved mental health status among these mothers. This correlation aligns with findings from other studies, which have similarly demonstrated the interplay between mental health and educational attainment [24, 25]. According to previous studies, a higher level of education is also significantly

associated with a better quality of life [28], which can be significantly influenced by mental health status as a study in Malaysia found that higher stress is significantly associated with lower quality of life for mothers with thalassemic children [29].

Social life is a significant determinant of anxiety in our study. Similarly, research in both Egypt and Malaysia has consistently shown a positive correlation between the presence of social support and the overall quality of life experienced by mothers raising children with thalassemia. These findings underscore the crucial role of social support as a potential determinant of the mental well-being of these mothers [28, 29]. Furthermore, the study in Malaysia emphasized the essential role of social support in mitigating the adverse impact of stress on the quality of life for mothers raising children with thalassemia [29]. On the other hand, quality of life is significantly and positively associated with socioeconomic level, as found by the study in Egypt, implying that mothers at lower socioeconomic levels receive less social support [28]. Therefore, the challenges faced by these mothers are notably more daunting when compared to their counterparts with higher socioeconomic status. This finding holds particular significance in the context of Bangladesh, where our study illuminated the prevalence of low family incomes among the majority of mothers caring for children with thalassemia, emphasizing the predominantly low socioeconomic status of thalassemia patients in the country.

The need for psychological, social, and economic support to cope with the challenges was emphasized by previous qualitative studies on the mothers of children with thalassemia [11, 13]. Regular counselling sessions for parents, educational programs for other family members, public awareness of thalassemia, and enhancing mothers' awareness of self-care were recommended in previous studies. All these are important because the thalassemia parents seek family cooperation, social support, and medical consultation to cope with the challenges [30]. A study in Iran identified the most common coping behaviour of the mothers of thalassemic children including reading about medical issues that worry them, praying to and trusting god, and self-counselling by saying that they have things to thank god for [30].

This follow-up study found that among the 365 cases, six patients died between 2018 and 2022, re-emphasizing the low survival rate of the patients due to inadequate treatment in developing countries like Bangladesh. Although the mental health status of the mothers who lost their child is beyond the scope of this study, previous studies have found that there is an increased risk of anxiety and depression among bereaved parents (who lost their child owing to a malignancy) compared with non-bereaved [31]. We can get a hint about this in our study too as we found a significant association of death due to thalassemia among extended family and relatives with the depression, anxiety, and stress of the mothers. As our study excluded bereaved mothers (who lost their child due to thalassemia), our measures of anxiety, depression, and stress would be underestimated. Moreover, the study in Sweden also found that psychological distress was overall higher among bereaved mothers than the bereaved fathers [31]. This makes our study on the mental health of mothers more relevant.

Limitations

The main limitation is recalling bias. Second, our study findings may not be generalizable to all thalassemia families in the country, especially patients from remote areas who are unable to travel to the capital city for regular medical treatment. Third, the findings may be significantly impacted by the low number of observations due to the high attrition rate of first-round cases. Fourth, behaviour and body language cannot be observed well in telephone interviews which can be a significant factor in measuring DASS-21 scores. Fifth, the pre-existing psychological condition of the people participating in the study is unknown, which can cause a bias in estimating the depression, anxiety and stress among them.

Conclusions

Like in many other parts of the world, caring for a child with thalassemia can be an emotionally challenging experience for mothers in Bangladesh. The majority of the mothers of children with thalassemia are found to have some level of depression, anxiety, or stress. An inherited blood condition called thalassemia necessitates regular, often intensive medical intervention. The chronic nature of the condition, coupled with the financial, social and physical burdens associated with its management, can contribute to elevated levels of depression, anxiety, and stress among mothers. The disease-related factors such as treatment cost and transfusion frequency are found to be the important determinants of the mental health status of the mothers.

Policymakers, support groups, and medical professionals must acknowledge and respond to the mental health needs of mothers raising and caring for thalassemia-affected children. Providing easily accessible and comprehensive support services, including counselling, support groups, and financial aid, can play a significant role in mitigating the psychological impact of thalassemia on mothers and improving the overall well-being of both the caregiver mothers and their children affected by the condition.

Abbreviations

ASPR	Age-standardized prevalence rates
BDT	Bangladeshi Taka

BTSH	Bangladesh Thalassaemia Samity Hospital
DASS-21	Depression, Anxiety and Stress Scale – 21 Items
REDCap	Research Electronic Data Capture
SD	Standard Deviation
SIM	Subscriber Identity Module
WHO	World Health Organisation

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Author contributions
MSH, FI, and ER conceived the idea and designed the study. FI, SS, SR, and AM were involved in data generation. FI analyzed data. FI, MSH, SS, SR prepared the first draft of the manuscript. All authors read, provided critical feedback and approved the manuscript.

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Data availability
The datasets used and/or analyzed during the current study are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate
The study protocol was approved by the institutional review board of the Biomedical Research Foundation, Bangladesh (Ref. no: BRF/ERB/2029/001). In accordance with the Declaration of Helsinki, written informed consent was taken from each participating mother in the first phase of the study. During follow-up study, verbal consent was taken from each participant during the telephone interview.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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