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Contributing Factors of Mental Stress among Parents of Thalassemia-Affected Children

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Abstract

Thalassemia is a chronic genetic disorder requiring lifelong treatment, which creates significant emotional and financial burdens for families. A cross-sectional study was conducted in the Departments of Hemato-oncology of Dhaka Shishu Hospital and Bangladesh Thalassemia Hospital, Dhaka, Bangladesh, from January to December of 2018, to identify the factors contributing to mental stress among parents of thalassemia-affected children. Data were collected using a pretested semi-structured questionnaire and the 'Parental Stress Scale' (PSS) to assess stress levels. 56.7% of the parents were female, with 63.8% being 40 years or younger. A majority of parents (61.7%) lived in rural areas, and 68.1% had a monthly family income of ≤20,000 BDT. Regarding the children's condition, 86.5% had one child with thalassemia, and 70.9% of parents could afford the treatment costs. The study also revealed that 77.3% of children required blood transfusions less than 30 days apart, and 54.6% required at least 12 transfusions per year. The average monthly drug and treatment costs were significant financial burdens on the parents. The mean PSS score was 58.2±4.6, with more than half of the parents (53.2%) experiencing high stress levels. The study found significant associations between PSS scores and factors such as the number of blood transfusions required, treatment assistance from others, and the reluctance to attend social events with affected children. This study highlights the substantial mental and financial stress faced by parents caring for children with thalassemia, underlining the need for targeted interventions to support these families.

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Introduction

Thalassemia is a hereditary, persistent illness that causes a hematological abnormality in the human body. Because of this, the disease ultimately results in anemia and demands continuous medical attention for the duration of the patient's life.[1,2] The "world thalassemia belt," which includes Southeast Asia, the Indian subcontinent, Mediterranean nations, and Middle Eastern nations, is marked by a high prevalence of thalassemia.[3] An estimated 15 billion individuals worldwide are thought to be affected by thalassemia illness[4], and in low and middle-income nations, 50,000 to 100,000 children perish away from thalassemia major each year.[5] They were formerly thought to be a tropical and subtropical disease, but due to migration of populations, they are now found throughout the world.[3] Though there are few reliable data, thalassemia is highly prevalent in Bangladesh. It has been discovered that 6–12% of people have characteristics associated with various hemoglobinopathies.[6] It is believed that there are

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between 60,000 and 70,000 individuals in Bangladesh who suffer from various degrees of beta major and Hb-E beta thalassemia. With the birth rate of 21.6/1000, it could be estimated that nearly 2500 thalassemia major cases are added every year in Bangladesh.[7]

The only curative treatment for thalassemia is bone marrow transplantation, which is only available to a small number of patients due to the high cost and morbidity associated with the procedure. Patients with severe forms of this disease need to receive regular blood transfusions and adequate iron chelation therapy in order to survive.[3] Since treatment for Thalassemia is not free in Bangladesh, the family of a child diagnosed with the disease must endure a significant financial burden.[8] Moreover, the psychological impact of living with a long-term condition and associated social stigmatization is also a heavy burden for the families in this part of the world.[9] Moreover, the existence of a chronic disease like thalassemia in children causes physical and psychological stress in parents and that can predispose them to psychological disorders.[6] The results of a study showed that the majority of families of children with thalassemia major had a high level of personal stress, and in general, 45.8% of the families tolerated high level of caregiver burden.[4] A study among Jordanian mothers having children with thalassemia revealed that mothers face various forms of stress, such as non-physical and cognitive stress, social segregation, and concerns about their children's future, which are further aggravated due to deficiency of knowledge and financial burden.[1] The mothers of thalassemic child are found anxious about their children's future education, work, and marriage, which caused turmoil in their lives.[10] The major issues faced by parents were financial expenditure, affected mutual relationships, and loss of interest.

Financial issues are the most important concern that increased the burden of the family having child with thalassemia. Increased expenses associated with treatment, transportation, and other living cost were the most cause of the burden for families.[11] Family well-being is definitely a foundation for children's quality of life.[12] Therefore, comprehending the factors related with psychological state of parents having thalassemic child can aid healthcare providers and managers in devising effective interventions that enhance the coping skills of parents, leading to better management of such challenges.

Methods

This cross-sectional study was conducted in the Departments of Hemato-oncology of Dhaka Shishu Hospital and Bangladesh Thalassemia Hospital, Dhaka, Bangladesh, from January to December of 2018. A total of 141 parents were selected from those two cetres through purposive sampling. Data were collected using a pretested semi-structured questionnaire through face-to-face interviews. The 'Parental Stress Scale' (PSS) was employed to assess the stress levels experienced by parents. Lower scores indicate a low level of stress, while higher scores indicate a higher level of stress.

The data were reviewed and cleaned, followed by creating a template, categorizing, coding, and recoding the data in IBM SPSS version 23.0 for windows. Descriptive analysis was conducted on the quantitative data, and an independent sample t-test was used to assess the significance of associations between variables. The results were presented in tables and pie charts.

The study was approved by the Institutional Review Board of National Institute of Preventive and Social Medicine (NIPSOM), Dhaka, Bangladesh (NIPSOM/IRB/2018/471).

Results

Table-I shows the sociodemographic characteristics of the parents of the thalassemia-affected children. The results revealed that 56.7% of the parents were female, and 63.8% were aged 40 years or younger (mean 36.2±8.8). Additionally, 73% of their spouses had an education level below a graduate degree, and 63.8% of the participants themselves had below-graduate education. The majority of respondents (61.7%) resided in rural areas, and 73.0% lived in nuclear families. Most parents (68.1%) had a monthly family income of ≤20,000. Table-II illustrates the factors contributing to mental stress in parents of children with thalassemia. Among the parents, 86.5% had one child with thalassemia, 12.8% had a thalassemic carrier child, and 15.6% had a history of consanguineous marriage. The mean number of living children was 2.2±0.4. The average drug cost for the previous month was 3258.7±4027.7 BDT, while the average treatment cost was 986.1±117.5 BDT. Furthermore, the mean cost of blood purchases in the previous month was 825.8±102.4 BDT. The majority of parents (70.9%) were able to afford treatment costs. In terms of thalassemia types, 55.3% of the children had β-thalassemia minor (HbE), and 44.7% had β-thalassemia major. 64.5% of the children had been diagnosed within the last 12 months. For most parents (77.3%), the interval between two consecutive blood transfusions was less than 30 days, and 54.6% of the children required at least 12 blood transfusions per year. Among children aged ≤36, 52.4% were using thalassemia medication. Only 10.6% of the children had a history of splenic surgery, and 12.1% had experienced the death of a thalassemic child. Regarding growth, 37.6% of the children had normal growth, while 62.4% showed delayed growth. Moreover, 39.7% of parents expressed concerns about recurrent complications from blood transfusions, and 17.0% were hesitant to attend social events with their affected child.

Fig. 1 exhibits that the mean PSS score was 58.2±4.6. Over half of the parents (53.2%) experienced high stress, while 34.2% had a moderate level of stress. Table-III shows the association of various factors with the mean PSS scores. Significant associations were found between PSS scale scores and the number of blood transfusions required per year (p=0.025), treatment assistance from other individuals (p=0.014), treatment support from various organizations (p=0.000), history of spleen operation (p=0.036), and reluctance to attend social events with the affected child (p=0.006).

Table-I: Sociodemographic status of the parents (n=141)

Variables		Frequency	Percentage
Age groups (in years)	≤40	90	63.8
	>40	51	36.2
	Mean±SD	36.2±8.8	
Sex	Male	61	43.3
	Female	80	56.7
Education	Illiterate	31	22.0
	Below graduate	90	63.8
	Graduate and above	20	14.2
Spouse's education	Illiterate	18	12.8
	Below graduate	103	73.0
	Graduate and above	20	14.2
Type of family	Nuclear	103	73.0
	Joint	38	27.0
Residence	Rural	87	61.7
	Urban	54	38.3
Monthly family income (in Taka)	≤20,000	96	68.1
	20,001-50,000	31	22.0
	≥50,001	14	9.9
	Mean±SD	27113.5±46696.9	

Table-II: Factors contributing to mental stress in parents of children with Thalassemia (n=141)

Variables		Frequency	Percentage
Factors related to family history			
Number of alive children	Mean±SD	2.2±0.4	
Number of children affected by Thalassemia	1	122	86.5
	2	19	13.5
	Mean±SD		1.0±0.2
Having a thalassemic carrier child	Yes	18	12.8
	No	123	87.2
Incidence of consanguineous marriage	Yes	22	15.6
	No	119	84.4
Factors influencing expenditures			
Medication expenses in the past month (in BDT)	Mean±SD	3258.7±4027.7	
Treatment expenses in the past month (in BDT)	Mean±SD	986.1±117.5	
Expenses for purchased blood in the past month (n=68)	Mean±SD	825.8±102.4	
Ability to afford treatment-related expenses	Capable of affording	100	70.9
	Unable to afford	41	29.1
Child health-related factors			
Respondents based on their child's type of Thalassemia	β-thalassemia major	63	44.7
	β-thalassemia minor	78	55.3
Thalassemia-affected children by diagnosis duration (in months)	≤12	91	64.5
	>12	50	35.5
Blood transfusions required in a year	≤12 times	77	54.6
	>12 times	64	45.4
	Mean±SD		15.6±8.4
Interval between 2 consecutive blood transfusions (in days)	≤30	109	77.3
	>30	32	22.7
	Mean±SD		35.2±11.6
Use of Thalassaemia medication by age in children with Thalassaemia (n=124)	≤36	65	52.4
	>36	59	47.6
	Mean±SD		48.5±26.4
History of spleen operation	Yes	15	10.6
	No	126	89.4
History of thalassemic child death	Yes	17	12.1
	No	124	87.9
Social relation related variables			
Growth comparison between Thalassemia-affected and non-Thalassemia children	Normal	53	37.6
	Delayed	88	62.4
Reluctant to attend a social program with the affected child	Yes	24	17.0
	No	117	83.0
Fear of recurring blood transfusion-related complications	Present	56	39.7
	Absent	85	60.3

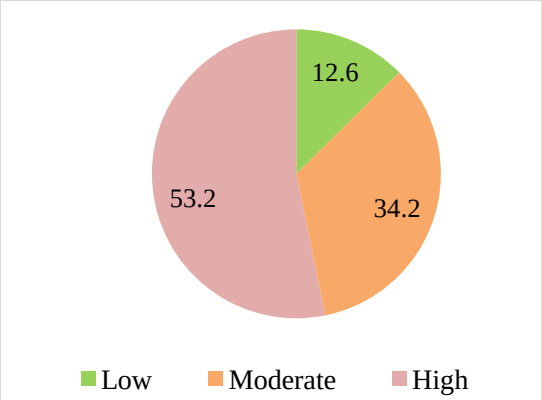

Fig. 1: Levels of stress by PSS scale scores (n=141)

Table-III: Association of different factors with mean PSS scores (n=141)

Variables	Category	PSS scores Mean±SD	p-value
Gender	Male	57.87±5.976	0.563
	Female	58.44±5.603	
Residence	Rural	58.70±4.698	0.226
	Urban	57.37±7.106	
Blood transfusions required in a year	≤12 times	57.21±6.047	0.025
	>12 times	59.38±5.181	
Treatment continued by help of other personal	Yes	60.33±4.553	0.014
	No	57.54±5.938	
Treatment continued by help of various organizations	Yes	61.87±3.730	0.000
	No	57.15±5.809	
History of spleen operation	Yes	61.13±5.111	0.036
	No	57.84±5.743	
Reluctant to attend a social program with the affected child	Yes	60.11±5.149	0.006
	No	57.29±5.825	

Independent sample t-test done, p<0.05 considered as statistically significant value

Discussion

The findings indicated that 63.8% of the parents were in the age range of ≤40 years (mean was 36.2±8.8).

In another study done in Malaysia found that the majority of mothers (43.3%) were aged between 31-40 years, which was almost similar to this study.[13] Aziz *et. al.* found that the majority of mothers (71%) with a mean age of 32±8.07 years.[14] The results showed that women made up the majority of the parents (56.7%). Another study reported that 34 (63%) of the 54 parents are mothers.[15] In terms of respondents' level of education, 63.8% of participants had below-graduate degrees, whilst 73% of their wives had less than a graduate degree. The majority of Malaysians 62.6% had finished secondary school, and 23.7% had completed higher education.[13] The majority of those surveyed (61.7%) were from rural areas, and 73.0% were from nuclear families. Most of the parents' family income in our study was ≤20,000 per month (68.1%). Nonetheless, a study conducted in Bangalore, India, reported that, out of 100 parents, 47% belonged to a nuclear family and 53% to a joint family. Of the population, 45% were from rural areas and 55% were from urban areas.16 Moreover, only 3% of them earned more than Rs. 20,000 per month, whereas 65% of them earned between Rs. 1,001-5,000.[16]

According to this study, 13.5% of parents had more than one thalassemic child, whereas 86.5% had just one. In Malaysia, evidence showed that 36% of the 372 respondents had two or more children, and 64% had one thalassemic child.[13] According to the study, first cousin consanguineous marriage plays a major influence in the illness process's persistence.[1] This survey revealed that 15.6% of respondents had a history of consanguineous marriage. Last month's mean medicine purchase price was 3258.65 taka. The increased expense of iron chelation therapy caused drug prices to rise, making it unaffordable for the majority of parents at the appropriate time. The average amount spent on treatment was 868.92 taka.

Age, body weight, and disease severity all affect treatment costs in Bangladesh.[7] The amount of money spent by each respondent for a single bag of blood transfusion varied. Furthermore, 825.8±102.4 was the mean of the expenses incurred for blood purchases throughout the month prior (n=68). According to Esmaeilzadeh *et al.* (2015), treating a thalassemic patient costs an average of 8321.8 USD per year. Of this number, the government bears 66% of the burden, insurance bears 15%, and parents bear only 19%.[17] However, the researcher discovered that neither the government nor insurance provided any assistance to any of the patients. According to the research in Bangladesh, the prevalence of E beta thalassemia, beta thalassemia major, and HbE illness among 432 afflicted children was 68.5%, 31%, and 0.5%, respectively. Furthermore, 51% beta thalassemia was diagnosed at less than 2 years of age whereas majority E beta Thalassemia was diagnosed at more than 2 years of age and only 10.8% children having E beta Thalassemia was diagnosed at below 2 years of age.[18] Similarly, E beta Thalassemia was most prevalent (55%) in this study. Then, 44% of people had beta thalassemia major, and 1% had beta thalassemia carrier. Majority of children (64.5%) was diagnosed within 1 year of age.

The percentage of thalassemic children who required up to 12 bags of blood in a year was 54.6%. In a year, another 45.4% required more than 12 bags of blood. In a comparable direction, Esmaeilzadeh *et al.* showed that, out of 102 patients, each patient received an average of 10.2±30.8 bags of blood annually.[17] The researcher discovered that 10.6% of children with thalassemic disorders had splenectomy as a kind of treatment. However, 29 out of 58 patients with beta thalassemia major required a splenectomy, according to a study conducted in the United States.[19] According to 17% of respondents; they are hesitant to attend social programs with children who have thalassemia. All children with thalassemic disease require frequent blood transfusions. Accordingly, 39.7% of responders were anxious about recurring complications after blood transfusions. In Malaysia, discovered that parents were constantly afraid about the negative effects of transfusion.[20]

The mean PSS score in this study was 58.2±4.6, and 53.2 percent of the parents reported high levels of stress. Similar findings were observed in Nepal, where 71.6% of parents reported a moderate level of psychological stress and the mean score was 47.47±10.9.[5] A few metrics revealed a statistically significant correlation between mental stress and the number of blood transfusions received in a given year ($p=0.002$). The majority of parents missed workdays due to normal medical procedures, particularly blood transfusions.[13] Those respondents who had a history of splenectomy of thalassemic child, they had higher level of mental stress; mental stress of respondents in relation to facing satire for having a thalassemic child; treatment continuation of the respondents by others help and mental stress was higher; treatment continuation of the respondents by different organization and mental stress was significantly higher ($p<0.05$); There was no association between mental stress in relation to their resident ($p<0.05$). Moreover, evidence showed that parents with lower income experience a greater psychosocial burden while caring for children with thalassemia.[5]

Conclusion

The mean PSS score was 58.2±4.6, with more than half of the parents (53.2%) experiencing high stress levels. The study found significant associations

between PSS scores and factors such as the number of blood transfusions required, treatment assistance from others, and the reluctance to attend social events with affected children. The results of our study unequivocally demonstrate that thalassemia is a stressful experience for parents, particularly for those with fewer opportunities for treatment and mental and psychological assistance. The results may improve care measures, such as counseling, by helping social workers and health professionals understand the significant stress that parents deal with when their children are diagnosed with thalassemia.

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