

Original Article



Mental Stress of Parents Having Thalassemic Children

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Abstract

Background: Thalassaemia is an emerging global public health concern. It is considering as a rapidly growing major health burden for low- and middle income countries. The prevalence of thalassaemia is increasing in Bangladesh, indicates that thalassaemia will be an emerging health burden for our country. **Objective:** To assess the level of mental stress among parents with a thalassaemic child. **Materials and Methods:** A cross-sectional study was conducted among the 141 parents with a thalassaemic child in the purposively selected two hospitals' Dhaka Shishu Hospital and Bangladesh Thalassaemia Hospital in Dhaka. 'Parental stress scale' (PSS) was used to measure the level of stress. **Results:** The mean age of the parents was 36.2±8.8 years and nearly two-thirds (63.8%) of them were aged below 40 years. Almost half of the participants (49.6%) and their spouses (59.6%) completed their education upto the higher secondary level. The mean monthly family income was 27,113.5±46,696.9 taka. More than half of the parent's (53.2%) had low level of mental stress. The education, occupation, monthly family income, presence of >1 thalassaemic child in family, received blood from a voluntary blood donor, normal growth of thalassaemic child and history of thalassaemic child death were significantly associated with the level of mental stress by PSS scores of the parents ($p < 0.05$). The level of stress was low among the parents, whose educational level was up to primary level (68.6%), occupation as a business (68.4%), monthly family income $\geq 50,001$ taka (85.7%), presence of >1 beta thalassaemia major child (47.6%), received blood from a voluntary blood donor (50.0%), had a history of normal growth of thalassaemic child (60.4%) and had no history of thalassaemic child death (50.0%). **Conclusion:** Existence of the children with thalassaemia in a family cause massive stress and anxiety for parents. Psychological supports for them are essential as a part of comprehensive medical care along with clinical management of the thalassaemic child. The burden of disease can be reduced through effective preventive approaches, such as carrier screening, prenatal counseling and diagnosis.

Key words: Mental Stress, Parenting, Thalassaemic Child, Bangladesh.

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Introduction

Thalassaemia is an autosomal recessive disorder and a hereditary haemoglobin disorder, which is a global public health concern, particularly in the developing countries.¹⁻³ In last few decades, the prevalence of this disorder increasing in the South-east Asia and also in Bangladesh.^{4,5} The most common combination of beta-thalassaemia with abnormal Hb or structural Hb variant with thalassaemic properties is HbE or beta-thalassaemia which are most prevalent in South-east Asia where the carrier frequency is around 50%.⁶ World Health Organization (WHO) estimates that globally about 6.5% of total populations

are carrying different inherited hemoglobin disorders. In Bangladesh, about 3% are carriers of beta-thalassaemia and 4% are carriers of Hb and in each year, more than 7000 children are born with thalassaemia. It is about 3.6 million carriers of beta-thalassaemia and 4.8 million carriers of HbE beta-thalassaemia.⁷

Thalassaemia is an emerging health burden for this country.⁸ It is a group of blood disorders resulting from the inheritance of mutated globin genes and decreased production of functional Hb, and eventually anaemia.⁹ Thalassaemic patients needed

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frequent hospitalization, because its management requires lifelong regular blood transfusion, with or without Iron Chelation Therapy. The patients with thalassaemic child have dealing frequent hospital visits and blood transfusions, which effect on their psychological state causing fear, depression and helplessness and resulting psychosocial burden. The family members also faced emotional distress, anxiety, difficulties in sharing with feelings and the normal family functions.¹⁰⁻¹² Thus a thalassaemic child and the families enduring a socio-economic pressure, which ultimately causes the burden for the whole community.¹³ Considering these, the researchers conducted this study to assess the mental stress among parents of children with thalassaemia.

Materials and Methods

A cross-sectional study was carried out to assess the level of mental stress among parents with a thalassaemic child. The study was initiated during the period January to December, 2018 in the purposively selected two hospitals named Bangladesh Thalassaemia Hospital and Dhaka Shishu Hospital situated in Dhaka, Bangladesh. Participants were 141 parents of the thalassaemic child who came to the Indoor Department (Hemato-oncology) of the hospitals for blood transfusion of their thalassaemic children with check-up and had a thalassaemic child with history of blood transfusion minimum 2 times.

Data were collected by using a pretested semi-structured questionnaire through face-to-face interviews with 141 eligible parents at their convenience. 'Parental stress scale' (PSS) was used to measure the levels of stress experienced by parents. Low scores signify a low level of stress and a high score signifies a high level of stress. The scale consists of 18 items, which were answered using a 5-point Likert scale with 1=strongly disagree to 5=strongly agree. The 8 positive items are reverse scored so that possible scores on the scale can range 18-90. The PSS scores are obtained by reversing responses (e.g.1=5, 2=4, 3=3, 4=2, 5=1) to the eight positively stated items (item 1, 2, 5, 6, 7, 8, 17 and 18) and then summing across all scale items. The PSS mean scores, low level of stress is below mean scores and high level of stress is above mean scores. Interpretation of mental stress based on PSS which is used the chi-square test to see the association. The data were checked and cleaned followed by making a template, categorizing data, coding and recoding into SPSS v23. The results were presented in tables and bar diagrams.

Participation was voluntary and confidentiality was maintained and informed written consent was taken from each participant. The study was validated by the National Institute of Preventive and Social Medicine (NIPSOM), Dhaka 1212, Bangladesh. (NIPSOM/IRB/2018/471)

Results

Table I characterizes the socio-demographic profile of 141 parents of thalassaemic children. The mean age was 36.2±8.8 years and nearly two-thirds of the parents (63.8%) were aged below 40 years. More than half (56.7%) were females. Nearly half of the participants (49.6%) and their spouses (59.6%) completed their education upto the higher secondary level. About two-thirds (73.0) came from nuclear families and the

mean monthly family income was 27,113.5±46,696.9 taka. Figure 1 illuminates that about half (48.9%) of interviewed participants were housewives and one-third of their spouses (34.0%) were also housewives.

Table II demonstrates the majority of the parents (70.9%) had ≤ 2 children. 13.5% of parents had more than 1 thalassaemic children and among them, 27.3% was thalassaemia carrier. 15.6% had a history of consanguineous marriage. Nearly half (46.1%) expensed more than 1,500 taka last month for drug therapy. More than one-fourth of parents (27.6%) were unable to bear treatment related expenditure. More than half (51.8%) of parents collected blood from the donor and 48.2% of parents purchased blood for the last blood transfusion. Among the blood donors, 17% were voluntary donors. More than half (55.3%) of children had HbE beta thalassaemia. About two-thirds of the children (64.5%) was diagnosed within 12 months from the interview. More than three-fourths children (77.3%) needed consecutive blood transfusions at less than 30 days intervals. About one in ten parents (12.1%) had a history of the death of a thalassaemic child. Nearly two-thirds of the children (62.4%) had a history of growth retardation. For attending a social program, 17.0% of parents felt hesitant and 39.7% of parents had anxiety about complications of repeated blood transfusions. More than three-fourths child (77.9%) had a history of drop out from school or college.

Figure 2 shows the level of mental stress. More than half of the parents (53.2%) had low level of mental stress and the rest had high level of mental stress.

Table III interprets that education, occupation, monthly family income, presence of >1 thalassaemic child, received blood from a voluntary blood donor, normal growth of thalassaemic child and history of thalassaemic child death were significantly associated with the level of mental stress by PSS scores of the parents (p<0.05).

Table I: Socio-demographic characteristics of arents having thalassaemic children (n=141)

	Characteristics	Frequency	Percent
Age groups (years)	20-29	35	24.8
	30-39	55	39.0
	40-49	38	27.0
	50-59	13	9.2
	Mean ± SD		36.2±8.8
Sex	Male	61	43.3
	Female	80	56.7
Education	Upto primary	51	36.2
	Uptohigher secondary	70	49.6
	Graduation and above	20	14.2
	Mean ± SD		36.2±8.8
Education of spouse	Upto primary	37	26.2
	Uptohigher secondary	84	59.6
	Graduation and above	20	14.1
Type of family	Nuclear	103	73.0
	Joint	38	27.0
Monthly family income (Taka)	≤10,000	40	28.4
	10,001-20,000	56	39.7
	20,001-50,000	31	22.0
	≥50,001	14	9.9
	Mean ± SD		27113.5±46696.9

Table II: Factors related to mental stress among parents with thalassaemic child.

Responses		Frequency	Percent
Family history			
Number of children (n=141)	≤2	100	70.9
	>2	41	29.1
Presence of >1 thalassaemic children (n=141)	Yes	19	13.5
	No	122	86.5
Presence of thalassaemic carrier children (n=66)	Yes	18	27.3
	No	48	72.7
Pre sence of consanguineous marriage (n=141)	Yes	22	15.6
	No	119	84.4
Income - expenditure related variables			
Expen diture for drug in last month (n=141)	≤1,500 taka	31	22.0
	1,501 -3,000 taka	36	25.5
	>3,000 taka	29	20.6
	Others (getting free or not need ed or no supply)	45	31.9
	Mean±SD	3258.7±4027.7	
Respondents according to their treatment related expenditure (n=141)	Able to done regular	100	70.9
	Unable to done regular	25	17.7
	Unable to done	14	9.9
	Free	2	1.4
Source of blood in last transfusion for thalassaemic children (n=141)	Purchased blood	68	48.2
	From donor	73	51.8
Received blood from a voluntary blood donor (n=141)	Yes	24	17.0
	No	55	39.0
	Occasionally	62	44.0
Child disease related variables			
Respondents according to their child's thalassaemia type (n=141)	Beta thalassaemia major	63	44.7
	Hb E beta thalassaemia	78	55.3
Thalassaemic child according to age of diagnosis (n=141)	1-6 months	60	42.5
	7-12 months	31	22.0
	Above 12 months	50	35.5
Thalassaemic child according to average interval of 2 consecutive blood transfusions (n=141)	8-15 days	34	24.1
	16-30 days	75	53.2
History of thalassaemic child death (n=141)	Yes	17	12.1
	No	124	87.9
Social relation related variables			
Normal growth of thalassaemic child (n=141)	Yes	53	37.6
	No	88	62.4
Feeling hesitation attending social program with thalassaemic child (n=141)	Yes	24	17.0
	No	117	83.0
Presence of anxiety for complication by repeated blood transfusion (n=141)	Yes	56	39.7
	No	85	60.3
Thalassaemic children according to absent from school or college (n=95)	Yes	74	77.9
	No	21	22.1

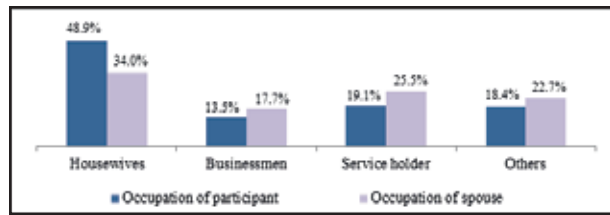


Figure 1: Occupation of the participants and their spouses (n=141)

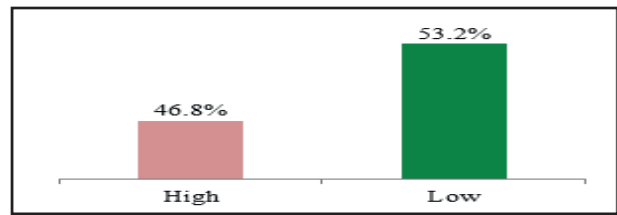


Figure 2: Level of mental stress by PSS scores

Table III: Association of different factors of parents with the level of mental stress by PSS scores

Factors		Level of mental stress			χ ² value	p-value
		Low	High	Total		
		n(%)	n(%)	n(%)		
Age groups (years)	20 -29	19(54.3)	16(45.7)	35 (100)	1.968	0.579
	30 -39	22(40.0)	33(60.0)	55 (100)		
	40 -49	19(50.0)	19(50.0)	38 (100)		
	50 -59	6(46.2)	7(53.8)	13 (100)		
Education	Upto primary	16(31.4)	35(68.6)	51 (100)	13.817	*0.001
	Upto higher secondary	34(48.6)	36(51.4)	70 (100)		
	Graduation and above	16(80.0)	4(20.0)	20 (100)		
Occupation	Housewife	34(49.3)	35(50.7)	69 (100)	7.923	*0.047
	Business	13(68.4)	6(31.6)	19 (100)		
	Service holder	12(44.4)	15(55.6)	27 (100)		
	Others	7(26.9)	19(73.1)	26 (100)		
Monthly family income (Taka)	≤ 10,000	13(32.5)	27(67.5)	40 (100)	17.653	*0.001
	10,001 -20,000	21(37.5)	35(62.5)	56 (100)		
	20,001 -50,000	20(64.5)	11(35.5)	31 (100)		
	≥ 50,001	12(85.7)	2(14.3)	14 (100)		
Type of thalassaemia	Beta major	30(47.6)	33(52.4)	63 (100)	0.030	0.862
	Hb E Beta	36(46.2)	42(53.8)	78 (100)		
Presence of >1 thalassaemic children	Yes	4(21.1)	15(78.9)	19 (100)	5.851	*0.016
	No	62(50.8)	60(49.2)	122 (100)		
Received blood from a voluntary blood donor	Yes	12(50.0)	12(50.0)	24 (100)	7.633	*0.022
	No	18(32.7)	37(67.3)	55 (100)		
	Occasionally	36(58.1)	26(41.9)	62 (100)		
Normal growth of thalassaemic child	Yes	32(60.4)	21(39.6)	53 (100)	6.280	*0.012
	No	34(38.6)	54(61.4)	88 (100)		
History of thalassaemic child death	Yes	4(23.5)	13(76.5)	17 (100)	4.207	*0.040
	No	62(50.0)	62(50.0)	124 (100)		

*Statistically significant value

Discussion

Thalassemic children usually suffer from severe chronic hemolytic anemia and need frequent blood transfusions at hospital settings. This chronic condition, it is a crucial source of stress for the parents and other family members.

The mean age of the parent was 36.2±8.8 years and nearly two-thirds of the parents (63.8%) were aged below 40 years. A study in Pakistan found 71% of mothers with a mean age of 32±8.07 years.¹⁴ Another study in Malaysia found 43.3% of mothers were aged between 31-40 years which is almost similar to our study.¹⁵ More than half (56.7%) were females, which is similar to the study in Malaysia.¹⁶ Nearly half of the participants (49.6%) and their spouses (59.6%) completed their education upto the higher secondary level, which is similar to the study in Malaysia.¹⁵ About half (48.9%) of interviewed parents and one-third of their spouses (34.0%) were housewives, which is similar to the study in India.¹⁷ About two-thirds (73.0) came from nuclear families, which is almost similar to the study in India.¹⁰ The mean monthly family income was 27,113.5±46,696.9 taka, which represents a low socioeconomic -Status of the participating parents.

In this study, the majority of the parents (70.9%) had ≤2 children. 13.5% of parents had more than 1 thalassaemic children and among them, 27.3% was a thalassaemia carrier. These findings are similar with the study in Malaysia.¹⁵ History of consanguineous marriage was present among the 15.6% of parents. Nearly half (46.1%) expensed more 1,500 taka last month for drug therapy. More than one-fourth of parents (27.6%) were unable to bear treatment related expenditure. More than half (51.8%) of parents collected blood from the donor and 48.2% of parents purchased blood for the last blood transfusion. They collected blood from only 17% of voluntary blood donors. More than half (55.3%) of children had HbE beta thalassaemia, which is similar to the study regarding thalassaemia prevention in Bangladesh.¹ About two-thirds of the child (64.5%) was diagnosed within 12 months from the interview. More than three-fourths child (77.3%) needed consecutive blood transfusions at less than 30 days intervals. These findings are similar to the study in Iran.² About one of ten parents (12.1%) had a history of the death of a thalassaemic child. Nearly two-thirds of the children (62.4%) had a history of growth retardation. For attending a social program, 17.0% of parents felt hesitant and 39.7% of parents had anxiety about complications of repeated blood transfusions.

More than half of the parent's (53.2%) had low level of mental stress and the rest, 46.8% had high mental stress. The education, occupation, monthly family income, presence of >1 thalassaemic child, received blood from a voluntary blood donor, normal growth of thalassaemic child and history of thalassaemic child death were significantly associated with the level of mental stress by PSS scores of the parents ($p<0.05$). The level of stress was low among the parents, whose educational level was upto primary level (68.6%), occupation as a business (68.4%), monthly family income ≥50,001 taka (85.7%), presence of >1 beta thalassaemia major child (47.6%), received blood from a voluntary blood donor (50.0%), had a history of normal growth of thalassaemic child (60.4%) and had no history of thalassaemic child death (50.0%).

Conclusion

This study has contributed information on mental stressors of the parents of thalassemic child. Most of the parents are facing the psychological, social and financial burden, because the children need lifelong treatment and blood transfusions. The treatment costs are high and ensuring availability of blood timely is also difficult for the parents. Implementation of comprehensive national integrated prevention programs such as public awareness and education, carrier screening, genetic counseling, premarital screening and prenatal diagnosis are necessary for the improvement of this inherited disorder in our country.

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