

Original Article

## PARENTING STRESS OF MOTHERS HAVING CHILDREN WITH THALASSEMIA

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### ABSTRACT

**Background:** Parents of children with thalassemia faces numerous challenges while coping various problems arises from the disease.

**Objective:** The study was conducted to assess parenting stress of the mothers having children with thalassemia.

**Materials and Methods:** This was a cross sectional study conducted among mothers having children with thalassemia. A total of 253 mothers were included in this study conveniently. Data were collected by face to face interview by using a semi-structured questionnaire. Data analysis were done by SPSS software. Level of stress was measured by using a modified parenting stress scale. The study was carried out during January to December 2016.

**Place and period of study:** This study was conducted in International Centre for Diarrhoeal Disease Research, Bangladesh (icDDR,b), Dhaka Shishu Hospital thalassemia center, Thalassemia foundation hospital and Bangabandhu Sheikh Mujib Medical University..

**Results:** The study revealed that 25-34 years age group was more (83.4%). Majority of the mothers was Muslim (97%), married (95%), educated up to SSC (64%), house wife (87%). Average monthly family income of the mothers was 26257 BDT and most of them were living in nuclear family (68%). Majority of the mothers had 2 children (82.2%), maximum was within 1-10 years age group (65.2%) and bearing child within 15-24 years (64%). Most of the mothers had male children (63%), received antenatal checkup (84%) and normal delivery (70%) at hospital (58%). Complication during pregnancy was found in few mothers (15%) and included malnutrition with anemia. Majority of the children were diagnosed thalassemia within 2 years of age (79.8%) and physical complications included reduced hemoglobin level and physical activity. Few thalassemic children had splenectomy (13%), majority of the children's condition was not improved (72%). Most of the respondents visited hospital once in a month (46%). Among all mothers, few had social support (28%) and greater part received financial support (84%). Majority of the mothers faced moderate level stress (52.2%). Mean of parenting stress was 40.16(±8.07). Minimum and maximum score of parenting stress was 22 and 59 respectively.

**Conclusion:** The parents having children with Thalassemia are burdened and under stress because of the chronic nature of the illness. All the findings suggests that time decisions with proper psychological supports and appropriate managements system can overcome the long term sufferings of the patients and thus reduce the stress of parents.

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**Key words:** Thalassemia, Parenting stress, Mothers, Children.

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### INTRODUCTION

Thalassemia is the most common inherited blood disorder in the world and passed on from parents to their children, causing an inability to produce adequate amount of haemoglobin and leading to severe haemolytic anemia. Dr. Cooley in USA first identified it on 1925. Hence it is also known as Cooley's anemia-Thalassemia International Federation (TIF). The two main types of thalassemia are  $\beta$  (beta) and  $\alpha$  (alpha). Both affect the production of normal haemoglobin -a key constituent of human red blood cells.

The choices available for an “at-risk” couple – when testing: three types of tests to determine whether an unborn child has thalassemia: Amniocentesis, Cordocentesis and Chorionic Villus Sampling (CVS), B. Genetic testing, C. Termination of pregnancy, D. Other approaches as analysis of fetal cells in the mother's blood, pre-implantation genetic diagnosis (PGD). The regular transfusion therapy with safe and appropriately processed blood, combined with regular and effective iron chelation tremendously increase patients' survival and quality of life.<sup>1</sup>

According to Prof. Waqar A Khan, nearly 14,000 thalassaemic children are born every year in Bangladesh.<sup>2</sup> Some studies shows parents who adapt less successfully to the Child's chronic illness tend to have a more negative and fatalistic attitude toward the child's illness. Children with Thalassemia have to regularly attend hospital for treatment. All these contribute to tremendous psychological pressure on the parents having children with Thalassemia. Parents suffer from psychosocial burden because of expenses, stress and fear of death. It is well known that psychological disturbances adversely affect compliance with treatment of thalassemia as in other chronic illnesses. A study refers 40% of the children had psychological problems and 74% had poor QOL.<sup>3</sup>

Parents of Thalassaemic patients not only have concerns regarding their children's goal, expectation and standard of life but also the impact of diagnosis and treatment on family stability and dynamics.<sup>4</sup> Marked development in the diagnosis and management has not been matched by progress in psychosocial rehabilitation of thalassemia patients.<sup>5</sup> On parents perspective it is a frightening and worrisome experience in which they have to cope up with the psychological aspects of Thalassemia along with their regular visits to the Thalassaemic centers for blood tests and blood transfusion with iron chelation therapy and their determination to fulfill the treatment.<sup>4</sup> The consequence of Thalassemia is extremely stressful and patients' face a variety of physical, psychological and social problems. Considering these experiences, in India Thalassemia might be officially considered as a disability, requiring a multiple theoretical as well as a prolonged intervention method to tackle it.<sup>6</sup> The increase risk of psychosocial and behavioral problems in Thalassaemics and their parents indicated the

both are carriers of  $\beta$  thalassemia – A. Prenatal importance of a lifelong psychosocial support for the prevention of mental health issues. The patients and parents who were more conscious of the illness were more worried but more compliant with the therapy and needed stronger psychiatric support.<sup>7</sup> Thalassemia greatly affects the psychosocial dimensions and a more structured long term psychosocial support is needed to improve quality of life of patients.<sup>8</sup> This study aimed to assess the level of parenting stress among the mothers having children with thalassemia.

## MATERIALS AND METHODS

This was a cross sectional study conducted among mothers having children with thalassemia and carried out from January to December 2016. The study places were hematology unit of International Centre for Diarrhoeal Disease Research, Bangladesh (icddr), Dhaka Shishu Hospital thalassemia center, Thalassemia foundation hospital and Bangabandhu Sheikh Mujib Medical University. A total of 253 mothers having diagnosed thalassaemic children willing to provide informed verbal consent were included as the respondents. Data were collected from conveniently selected participants doing face to face interview by using a pretested semi structured questionnaire. Parental stress scale and parenting stress index were modified used to assess the level of parenting stress. Data were analyzed by using SPSS software and the overall findings are presented through tables and appropriate graphs.

## RESULTS

Total of 253 mothers of thalassaemic children were selected through convenient sampling method. More than two third (83.4%) of the mothers were in 25-49 years of age group and 97% were Muslim (Table-1). Almost all (95%) of the mothers were married. Among the total respondents, educational qualification found up to SSC (64%) with a good numbers were HSC and above (27.7%). Over three fourth (87%) respondents were housewife. Above two third (89.3%) mothers monthly family income were <5000 BDT with an average of 26257 BDT. More than half (68%) mothers were living in nuclear family and over two third mothers (82.2%) were having up to 2 children. More than half (65.2%) of the thalassemia children's were found within 1-10 years age group (Table-1).

**Table 1: Socioeconomic characteristics of mothers having children with thalassemia**

<b>Variables</b>	<b>Frequency</b>	<b>Percent</b>
No of participants	253	100
<b>Age groups</b>		
<25 years	36	14.2
25-49 years	211	83.4
>50 years	6	2.4
<b>Religion</b>		
Muslim	245	97
Hindu	8	3
<b>Marital Status</b>		
Married	241	95
Widow	9	4
Separated	3	1
<b>Educational status</b>		
Informal	21	8.3
Up to SSC	162	64
HSC & above	70	27.7
<b>Occupation</b>		
Housewife	220	87
Teacher	8	3.2
Banker	7	2.8
Private sector job	11	4.3
Others	7	2.8
<b>Monthly family income</b>		
< 50000 BDT	226	89.3
> 51000 BDT	27	10.7
<b>Types of family</b>		
Nuclear	173	68
Joint	78	31
Extended	2	1
<b>Number of children</b>		
Up to 2	208	82.2
3-4	38	15
≥ 5	7	2.8
<b>Age of the children</b>		
1-10 years	165	65.2
11-20 years	79	31.2
21-30 years	9	3.6

More than half (64%) mother's child bearing age group were 15-25 years and 63% were male children.

84% of the respondents were received regular antenatal checkup (Table-2).

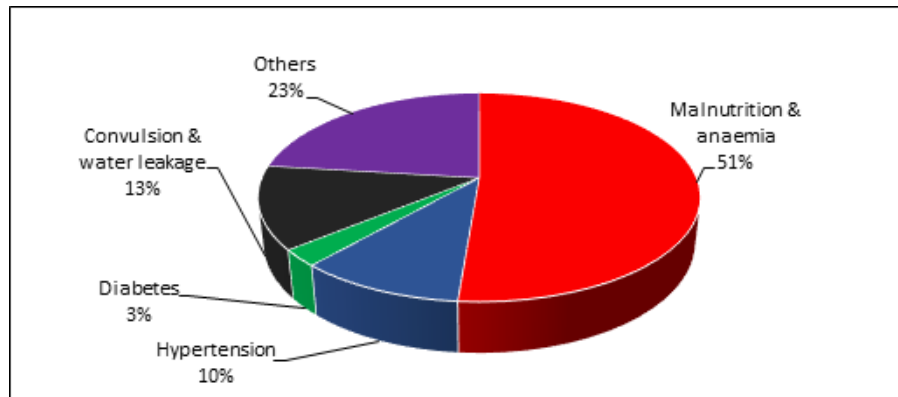
**Table 2: Factors of parenting stress among mothers having thalassemia children.**

Variables	Frequency	Percent
<b>Child bearing age</b>		
15-24 years	162	64
25-34 years	83	32.8
35-44 years	8	3.2
<b>Sex of the children</b>		
Boy	159	63
Girl	94	37
<b>Receiving ANC</b>		
Yes	213	84
No	40	16
<b>Place of delivery</b>		
Hospital	147	58
Home	106	42
<b>Mode of delivery</b>		
Normal	176	70
Caesarian section	77	30
<b>Thalassemia diagnosis age group</b>		
Upto2 years	202	79.8
2.1-4 years	27	10.7
4.1-6 years	15	5.9
≥ 6.1 years	9	3.6
<b>Improvement of the child getting treatment</b>		
Improved	71	28
Not improved	182	72
<b>Frequency of hospital visit</b>		
Once in a month	117	46
Twice in a month	98	39
More than twice in a month	6	2
Irregular	32	13
<b>Monthly treatment cost</b>		
1-5000 BDT	146	57.7
5000-10000 BDT	83	32.8
>10000 BDT	24	9.5
<b>Types of social support (N=76)</b>		
Financial help	64	84
Mental support	9	12
Care during illness	3	4

Among all the participants only 39 mothers had complications during pregnancy and half (51%) of

them were suffered from malnutrition and anaemia (Figure-1).

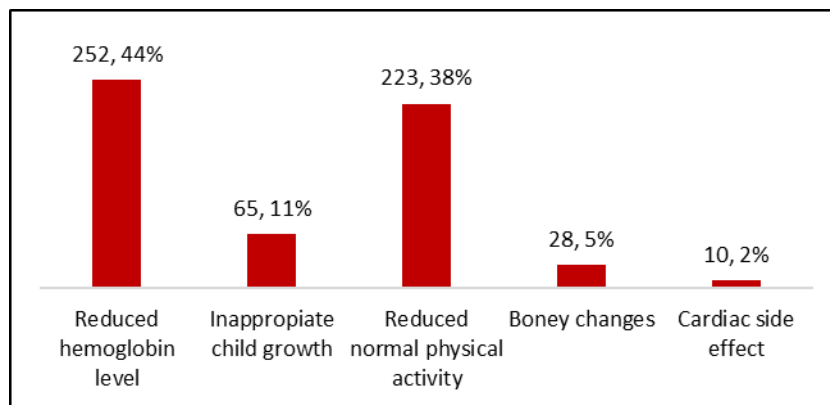
**Figure 1: Distribution of the mothers by types of complication during pregnancy. (N=39)**



Nearly three fourth (70%) mothers gave normal delivery and more than half (58%) of the mothers gave birth of child at hospital (Table-2). Majority (79.8%) of the children of respondents were

diagnosed thalassemia within 2 years age (Table-2). Nearly half (44%) of the thalassemia childrens found to have reduced haemoglobin level in blood as a physical complication (Figure-2).

**Figure 2: Distribution of the mothers by types of physical complications of thalassamic children. (N= 578)**



\* Due to multiple answers number of respondents had increased

Mostly regular blood transfusion (45%) and iron chelating drugs (41%) were observed as treatment pattern in this study (Figure-3). Majority (72%) of the diagnosed thalassemia children’s condition was not improved by receiving treatment. Almost half (46%) of the mothers visited hospital once in a month with the children and 57.7% respondents expenses almost 5000 BDT monthly for the treatment purpose.

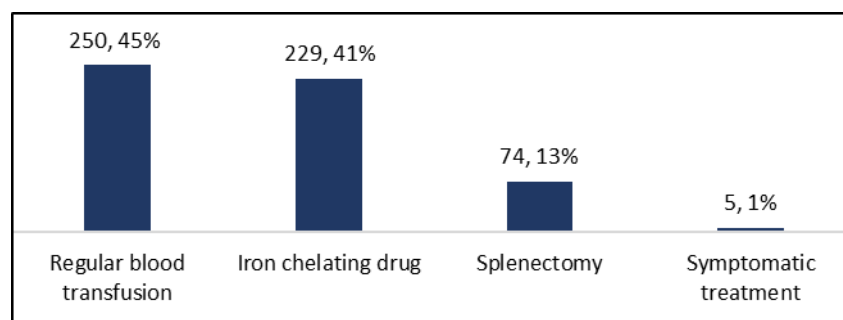
Out of total respondents,76 mothers were found having social supports in different manners, among

them 84% had financial help (Table-2). In this studyhalf (52%) of the mothers of diagnosed thalassemia children were suffering from moderate level of stress (Table-3).

There was no statistically significant relationship observed between parenting stress and age, occupational status, monthly income, family type, treatment cost of the respondents.

**Table 3: Level of parenting stress among mothers of thalassemia children**

Level of stress	Frequency	Percent
Mild stress (21-40)	119	47.0
Moderate stress (41-60)	132	52.2
Severe stress ( $\geq 61$ )	2	.8
Total	253	100

**Figure 3: Distribution of the mothers by treatment pattern of the children. (N=558)**

\* Due to multiple answers number of respondents had increased

## DISCUSSION

In this study, average age of the mothers was 31.59 ( $\pm 7.192$ ) years. Majority (97%) were Muslims as Bangladesh is a Muslim based country, its consistent with the national figure, which shows proportion of Muslim to be 89% (Demographics of Bangladesh 2013). Almost all 95% mothers were married. More than half (64%) of the mothers were found educated up to SSC with a good numbers were HSC and above (27.7%) which nearly corresponds with the study of Sandra.<sup>9</sup> Higher educated mothers usually have overprotective attitudes towards their ill children.<sup>10</sup> In this study, 87% respondents were housewives which accords to Wahab<sup>8</sup> and Tuladhar.<sup>11</sup> The average monthly family income was found 26257 ( $\pm 19325$ ) taka and 56.9% mothers monthly family income was 1000-20000 taka which seems higher than another study by Sandra.<sup>9</sup> As this study samples were collected from Dhaka city, more than half 68% parents belonged to nuclear family. A study at Bangalore, India done in urban area revealed that 53% parents belonged from extended family.<sup>9</sup> These two data differentiated the family type between urban and rural area. Majority 82% of the mothers had 2 children, 65% children were in 1-10 years of age group and Mean age was 8.92 ( $\pm 5.11$ ). Another study by Sandra<sup>9</sup> revealed majority of thalassemia children's age group was 0.7-15 years with mean age 7.7 ( $\pm 41.1$ ) which nearly relates to this study.

Three fourth (84%) respondents did regular antenatal checkup which closure to another study by Semasaka *et al*<sup>12</sup> and only 15% had complication during their pregnancy. Almost half (58%) of the mothers delivered their child at hospital and 70% did normal delivery. The present study showed higher antenatal checkup results less complication during pregnancy which similar to Tuladhar's observations.<sup>11</sup> Maternal complications occurred commonly in woman without ANC. In this study 51% pregnant woman had malnutrition and anemia, 10% hypertension and 3% diabetes which is very higher than the observations by Semasaka *et al*.<sup>12</sup> Results of regular ANC regarding less complication during pregnancy and healthy status of child after birth are due to development of healthcare delivery center both in public and private were increased and easily assessable to these for available transport facilities and increased consciousness of family members for better health of mother and children.

Here among all thalassemic children, boys were higher than girls which corresponds similar picture to Trehan *et al*<sup>13</sup> and Sandra.<sup>9</sup> Average child bearing age of the mothers was 22.9 ( $\pm 5.15$ ) year. 80% thalassemia children was diagnosed within 2 years of age which nearly relates to an observations from a study at Chandigarh, India.<sup>13</sup> Reduced hemoglobin level (44%) and less physical activity (38%) were common physical complications found among thalassemic children. Though multiple replies of the

respondents found in this study, regular blood transfusion (45%) and Iron chelating drug (41%) were frequently used as treatment for the thalassemia children in this study which is commonly found in different studies. A good number (13%) of splenectomy also done which found much lesser than an observation from Taha *et al.*<sup>14</sup>

Present study refers three fourth child's condition wasn't improved while getting treatment. Among the total respondents 13% visited hospital irregularly with the thalassamic children. In developing world, especially Bangladesh, poor availability of proper medical care, safe and adequate blood transfusions along with high cost medicines, lifelong treatment duration majority of patients couldn't afford proper treatment and suffered with the complications as well.<sup>2, 15</sup> More than half of the respondents expense up to 5000 BDT monthly for the treatment purpose of the thalassemic child which could be a financially burden to lower income families. It is reported in some studies that thalassamic patients suffers from some sort of mental health problems like depression, loneliness, anxiety, fear of death and aggression which focused the psychological supports of patients<sup>16</sup>. Only one fourth respondents had social supports in this study and among them majority had financial support and only few had mental supports. Travelling towards hospital, doctor visits with treatment expenditure and living cost impacts on thalassamic patients and family as well<sup>8</sup>. On the economic context of our country, financial issue had been a great concern revealed in this study. The chronicity and complications of Thalassemia affect the quality of life of victims and parents. As there is no definitive cure for this disease, the majority exclusively depend on blood transfusions as a treatment option that creates a burden not only on health system but also on affected families. This makes such families vulnerable to economic and psychosocial problems.<sup>17</sup>

A study by Sandra<sup>9</sup> showed majority (77.3%) of the samples expressed moderate stress and 21% had mild stress. In a study done by Pruthi<sup>18</sup> in Delhi, found 57% caregivers had psychiatric problems with depressive disorders. Another study conducted in Pakistan, 29% parents found moderate to severe depression and 3% severe depression due to thalassemia of their children.<sup>19</sup> But present cross sectional study showing more than half (52.2%) of the thalassamic children's mothers were faced moderate level of stress and 47% faced mild stress which implies dissimilarities with those of the previous studies. There was no significant relationship observed between age, occupational

status, monthly income, family type and treatment cost with parenting stress of the respondents.

## CONCLUSION

Thalassemia one of the commonest autosomal recessive disorder worldwide and also a major public health problem. From the above discussion it is noted that related to poverty, low education, monthly family income, frequent hospital visits, treatment costs, social support etc have impact on mothers of thalassemic children. The total scenario affects the psychological aspect of patients and parents. To address these problems as well as parenting stress a holistic approach of genetic counselling, psychological counselling, prenatal diagnosis, community awareness, study, mass media must be used. Above all, we should motivate, support, and encourage studies and research for further improved prevention strategies and clinical care for minimize the parenting stress.

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