

# The Psychosocial and Financial Ramifications of Thalassemia on Parents of Thalassemic Children Presented at Tertiary Care Hospitals

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## Abstract

Thalassemia major is a disease that requires frequent admission of patients to medical facilities along with unremitting medicinal and blood transfusion aids. The families of such patients suffer in different aspects of their lives. The severity of the challenges they are subject to has been examined in this research with reference to Karachi and Hyderabad. Chief focus is rendered to the assessment of psychological, social, and economical implications. **Objective:** The aim of this study is to assess the social, financial and psychological impact of thalassemia on parents of children suffering from thalassemia. **Study Design:** Cross-sectional study. **Place and Duration of Study:** The study was conducted at PNS Shifa Hospital Karachi, Jinnah Post Graduate Medical Institute Karachi, and Civil Hospital Hyderabad. **Methodology:** A cross-sectional study which was aimed at establishing the social, financial and psychological impact of thalassemia on families of affected children was conducted at PNS Shifa Hospital, Jinnah Post Graduate Medical Institute Karachi, and Civil Hospital Hyderabad. The data was collected using a structured questionnaire as tool for data collection. The questionnaires were filled by interviewing the parents of registered thalassemia major patients by the researchers. Data was analyzed and interpreted using the SPSS 25.0 version. **Results:** The total number of participants which were meeting the inclusion criteria was 237. Study population with high income (above PK rupees 35,000) is demonstrated to be less severely affected than the low earning study group. 17% of the parents in the study admitted to having negative impact of their child's illness on their relationship while 40% of study participants reveal their child is ignored/marginalized by relatives. About 80% of participants acknowledged feeling sad and depressed sometimes but only 25% of them take antidepressant medication.

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## Keywords

Thalassemia Major, Social, Financial Impact

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## 1. Introduction

Estimated 7% of world population is carrier of hemoglobin disorders [1] and approximately 1.5% of world population carries gene for beta Thalassemia [2]. Each year, 50,000 to 100,000 children die of thalassemia major in low and middle income countries [1]. Worldwide incidence level is estimated as 1 in every 100,000 [3]. Unfortunately, in Pakistan the number of children affected with transfusion dependent thalassemia is relatively higher than in most countries [4]. This is attributed to factors such as high frequency of gene, consanguineous marriages, high birth rate and rapidly increasing population [5]. Presence of thalassemia has been observed in all parts of the country [4]. Every year, 5000 children are born with thalassemia major in Pakistan, which puts the estimate of affected children in 5 out of 100, with the carrier rate being 5% [6] [7]. Furthermore, it was found in a study that children affected with refractory anemia had 83% chances to be detected with beta thalassemia [8]. A wide phenotypic spectrum of thalassemia has been observed and  $\beta$ -thalassemia major is a severe transfusion-dependent form of the disease, associated with various different complications that are caused by tissue hypoxia and also because of iron overload. Repeated transfusions and increased intestinal iron absorption are the two main sources of iron overload [9].

In developing countries lack of competence in dealing effectively with the disease arises due to a number of factors [10]. B-thalassemia is renowned as the most commonly occurring disorder in the inherited hematological and single gene disorders family [11] [12]. In this disorder, a reduced production of hemoglobin is observed causing a severe case of anemia among patients [13]. Hemoglobin molecule is primarily composed of two of each alpha and beta chains, characterized by their formation [3] [13]. Due to a defect in messenger RNA, the beta chain acquires an erroneous synthesis causing a deformation of RBCs [14]. The occurrence of severe anemia requires the patients to be transfused with blood at regular intervals along with iron chelation therapy and sometimes bone marrow transplantation [15] [16]. However, the compliance with treatment poses several challenges to the families of the affected individuals [17].

In thalassemia, patient serum ferritin detects total body iron, if the level of ferritin is above 2500 mg/d, in 15 years, this leads to multiple complications such as cardiac disease. Parents of thalassemic children are also concerned about many other problems such as bony deformity, appearance of the child, poor self-image, short stature delayed sexual development, and frequent hospital visits. Hemosiderosis is a major cause of mortality in these patients [1] [18]. Such patients also develop complication like cardiovascular diseases infections, bone

defects and diabetes [19]. Thalassaemic patients can only be cured by bone marrow transplant but unfortunately is beyond the reach of majority of the families in Pakistan [20].

In high-income countries, to prevent the disease related complications and improve outcomes for thalassemia patients variable measures are implemented such as the provision of safe blood transfusions, oral and parenteral iron chelating agents, noninvasive and regular iron monitoring, plus many other methods of supportive care [21] [22].

These challenges are examined separately in this study with the context of psychological, financial and social aspects.

## 2. Methodology

This cross-sectional study was carried out at PNS Shifa Hospital Karachi, Jinnah Post Graduate Institute Karachi, and Civil Hospital Hyderabad. Data was collected based on a structured questionnaire. Parents of children suffering from transfusion dependent thalassemia major were included in the study. Data collection spanned over a period of 6 months, from June 2018 to December 2018. The sample size was determined to be 237, as calculated by standard formula. The Parents were interviewed using a preset questionnaire by the researcher after acquisition of verbal consent from each participant and explaining the aims and objectives of the study.

Questions concerning the educational status of parents, monthly income, expenses on travelling to hospital, transfusions, chelating medicines, social life of parents and how their child's terminal illness affects their relationship and mental health were included. Data collected was analyzed through software SPSS version 25. This study has been approved by ethical review committee of Bahria University Medical and Dental College. **Reference No: ERC 57/2018.**

## 3. Sample Size

Sample size was calculated from online software openepi.com version 3. The statistical parameters were 95% confidence 5% margin of error. Population size for finite population correction factor  $N = 100,000$  and prevalence of beta thalassemia was 5% (reference study). The required sample size was 237.

Formula used was,

$$\text{Sample size} = \left[ \text{DEFF} * Np(1-p) \right] / \left[ \left( d^2 / Z_{1-\alpha/2}^2 * (N-1) \right) + p * (1-p) \right]$$

## 4. Results

Results obtained from the data are analyzed from the tabulated frequencies attained through utilization of SPSS 25 incorporating frequency analysis, crosstab analysis and chi square tests.

### 4.1. Financial Ramifications

Participants of the study classified according to their monthly income are ag-

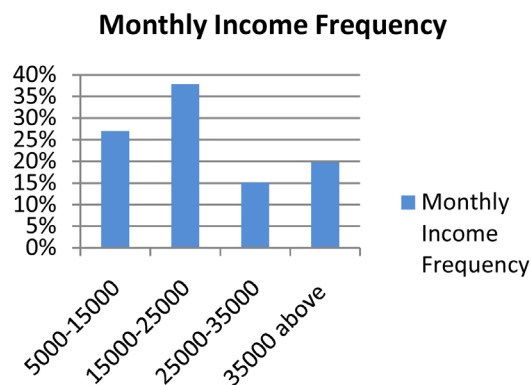
gregated into **Figure 1**.

**Figure 2** demonstrates the frequency attained comprehensively with financial ramification and their light, moderate and severe impacts upon participants ( $n = 237$ ).

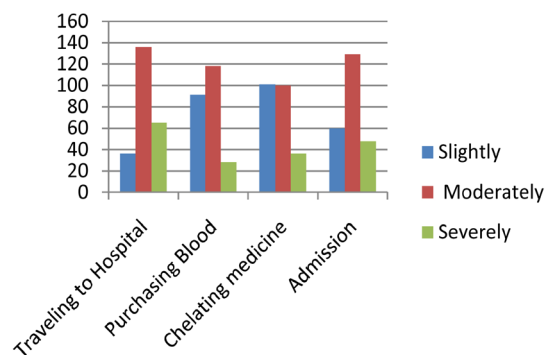
Frequent admission to the hospital affected 25% ( $n = 60$ ) populations lightly, with 54% ( $n = 129$ ) having moderate and 20% ( $n = 48$ ) having severe repercussions on the financial stability. Crosstab analysis represented higher income group as being affected less severely (12%) and lowest income affected more severely (28%). Chi square test analysis represented the  $p$  value to be 0.007, indicating a relation among the two variables. Cross analysis of purchasing blood and monthly income demonstrated slight effect on income group above-35,000 with 8% admitting severe effects. In contrast, lowest income group participants were affected severely with 26% result acquisition. Similar patterns were observed in bivariate analysis of travelling to hospital and purchasing medicine with monthly income with chi square tests representing the  $p$  value to be 0.003 and 0.000 respectively as attained from SPSS 25.

#### 4.2. Social Ramifications

In **Table 1**, frequencies evaluated from the responses generated from the data are tabulated against each variable. In response of how conditions of their lives were affected due to having a thalassemia major patient in the family, 31.2% ( $n =$



**Figure 1.** Monthly income frequency of participants.



**Figure 2.** Aggregates of financial ramifications.

**Table 1.** Social ramifications variables analysis.

Variable	(n)	Percentage (%)
<b>Affected relation with spouse</b>		
Yes	41	17.30%
No	196	82.70%
<b>Child stigmatized by relatives</b>		
Yes	95	40.1%
No	142	59.9%
<b>Lesser attention to other children</b>		
Yes	47	19.8%
No	88	37.1%
May be	102	43%
<b>Education of father</b>		
Illiterate	45	19%
Matric	80	33.8%
Intermediate	57	24.1%
Graduate	55	23.2%
<b>Education of mother</b>		
Illiterate	111	46.8%
Matric	75	31.6%
Intermediate	37	15.6%
Graduate	14	5.9%

**Table 2.** Psychological ramifications of variables analysis.

Variable	(n)	Percentage %
<b>Feel depressed or sad</b>		
Yes	190	80.2
No	47	19.8
<b>How often do you feel depressed</b>		
Everyday	64	33.7%
Once a week	87	45.8%
Once in a month	39	20.5%
<b>Take medicine for depression</b>		
Yes	58	24.5%
No	179	75.5%
<b>Feel intolerant of things</b>		
Not at all	21	8.9%
Sometimes	160	67.5%
Most of the time	56	23.6%
<b>Unable to get enjoyment</b>		
Not at all	19	8%
Sometimes	137	57.8%
Most of the times	81	34.2%
<b>Scared thinking grief of child</b>		
Not at all	8	3.4%
Sometimes	139	58.6%
Most of the times	90	38%

74) of the participants agreed to have acquired financial constraints along with finding it challenging to manage routine activities effectively.

### 4.3. Psychological Ramifications

**Table 2** shows that 80% of the participants acknowledged feeling depressed or sad, with 78% agreeing for recurrence every day or once a week. Upon being asked if they took any medicine for coping with depression 75% responded negatively. 67% of participants identified exhibiting intolerance some of the times with 92% recognizing they were unable to attain any form of enjoyment in their lives some or most of the times. 96% (n = 229) of the interviewees acknowledged that they were scared about thinking of the grief of their affected child. 92% (n = 218) of the participants conceded to have felt desolated or hopeless about the future some or most of the time.

## 5. Discussion

Thalassemia major is a chronic, lifelong illness, requiring scheduled blood transfusion, regular medicines and repeated hospital visits, which place patients and their families under great psychological and financial burden. The primary purpose of this study was to evaluate the impact on families of thalassemia major patients in three distinctive areas. The data generated from the questionnaire and evaluated in the results has equipped us with the ability to form a few inferences. Financially, it was observed that lower income class families, mostly from the PK Rupees 5000 - 15,000 monthly income group, were affected the most in contrast to the higher income groups. 83% admitted to having financial constraints with 74% severely affected by purchasing blood, medicines, traveling to hospital and admissions. A study conducted in Multan produced similar results [23]. A study conducted in Srilanka showed 30% of families had severe economic problems [24]. Irrespective of the income classes, the responses centered majorly on moderate scale (**Figure 2**). However, through chi square tests, the p value obtained enabled us to deduce the inferences in significance of the income classes. Furthermore, among social implications it was observed that the ratio of illiteracy in mothers of the affected patients was higher in comparison with fathers. 17.3% respondents had confessed to have troubled relationship with their spouse as a consequence of dealing with the child's illness, while it was 23% in another study [25]. 39% participants revealed lack of support from relatives. 62% participants had difficulty managing routine activities, similar to another research that was conducted [25]. This study revealed that 19.8% feel they give lesser attention to other children because of their child disease. 80% participants reported to feel depressed or sad, 24% take medication for depression. In a study conducted in Multan 29% parents had moderate to severe depression while 3% had severe depression [20]. The study shows that 92% participants felt there is nothing in the future to be hopeful regarding their child's terminal illness. Through this analysis it can be concluded that psychological implications on the

families of thalassemia major patients are significant.

## 6. Conclusion

Through the findings of this research it was established that lower income classes had a higher chance of suffering economically due to presence of a child suffering from thalassemia major. Adverse consequences of the disease on mental health of the families of affected children were also deduced.

## Author Contributions

Conception and design: Nimra Shafi, Shakeel Ahmed;

Collection of data: Nimra Shafi, Abdul Raheem;

Analysis and interpretation of data: Nimra Shafi, Shakeel Ahmed;

Statistical analysis: Faisal Fahim;

Drafting of article: Nimra Shafi;

Critical review of article: Shakeel Ahmed.

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## Conflicts of Interest

The authors declare that there is no conflict of interest.

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