

## Psychological Distress and Coping Strategies among Parents of Beta-Thalassemia Major Patients

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**Abstract.**  $\beta$ -Thalassemia major is a disorder characterized by defective production of hemoglobin and excessive destruction of red blood cells. The usual treatment consists of periodic blood transfusions that can cause iron overload within tissues. Parents of thalassemic 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 family dynamics. The present study focuses on psychological well being of parents of thalassemic patients.

**Key Words:**  $\beta$ -Thalassemia major, Puberty, Psychological distress

### 1. Introduction

$\beta$ -Thalassemia major is a disorder characterized by defective production of hemoglobin and excessive destruction of red blood cells. Hemoglobin (Hb) is formed of four protein subunits, two  $\alpha$  and two  $\beta$ . Genetic mutations in the gene encoding for the  $\beta$  subunits of the protein, result in reduced or totally absent synthesis of the globin  $\beta$ -chains, leading to the formation of abnormal hemoglobin or even to the absence of  $\beta$  hemoglobin. This defect causes an abnormal development of red blood cells and ultimately anemia, which is the characteristic symptom of the thalassemia. The disease is prevalent among Mediterranean people; the highest frequency is found in the Greek islands, in Italy and in Asia, where the highest concentration of people carrying the genetic mutations underlying thalassemia is found in the Maldives(1).

The usual treatment consists of periodic blood transfusions that can cause iron overload within tissues. Children on hypertransfusion regimes will maintain normal growth up to puberty. Serum ferritin gives an estimate of the total body iron; levels higher than 2500 mg/l over a period of 15 years are considered a risk factor for cardiac disease(1). The concept of health is described by WHO as "a state of complete physical, mental, and social well-being, not merely the absence of disease ...." Like any other chronic disease, for Beta-thalassemia, there is clinical burden on the whole family which includes psychological and social consequences which ultimately affects the well being of the patient(2). So it is imperative to study the psychological factors which incorporate, add to distress of the family alongside other factors. Previous studies focused on these points have shown improvement in the quality of life of such patients and their ability to integrate well into their society (2).

Parents of thalassemic 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 family dynamics. The disease related concerns of parents are regarding the appearance of their child, bone deformities, short stature, poor self-image, frequent hospital visits for transfusion, delayed or absent sexual development and impaired fertility and other associated complications such as heart disease, bone disease, diabetes, infections etc(3). On parent's perspective it is a frightening and worrisome experience in which they have to cope up with the psychosocial aspects of thalassemia along with their regular visits to the thalassemic centers for blood tests

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and blood transfusion with iron chelation therapy and their determination to fulfill the treatment. Parents of  $\beta$ -thalassemic patients undergo a significant psychological impact, causing emotional burden, hopelessness, and difficulty with social integration. They experience negative thoughts about their life, guilt, increased anxiety and low self-esteem. They have severe psychosocial problems due to their inability to cope up with painful situation which leads to worsenning of relationship amongst family members, increased marginalization and isolation. The present study focuses on psychological well being of parents of thalassemic patients. The parents of thalassemic patients elaborate a painful perception of the disease and show impairment in domains involved in physical health, psychological health, quality of life. Poor quality of life (QOL) of parents can be explained by a sense of guilt for having generated a child with a genetically determined disease.

## **2. Material and Methods**

This prospective, cross sectional study was carried out on Parents of Beta-Thalassemia Major Patients attending thalassemia centre in Rawalpindi, from May 2010 to April 2011. Forty parents (17 Fathers, 23 mothers) were included into the study. After obtaining informed consent, parents coming for regular treatment were asked to complete the questionnaire in the clinic.

### **2.1 Study Measures**

The psychological distress was assessed using the Parental Stress Scale (PSS) and General Health Questionnaire (GHQ) and coping strategies were assessed using COPE Inventory.

### **2.2 Parental Stress Scale**

The Parental Stress scale (PSS) is a 19-item self-report measure of parental stress which was developed by Berry & Jones (1995). Parents were asked to agree or disagree with items in terms of their typical relationship with their child and to rate each item on a five-point scale: strongly disagree (1), disagree (2), undecided (3), agree (4), and strongly agree (5). The scores on the scale range between 18-90. Higher scores on the scale indicate greater stress and low score indicate lesser stress. The Parental Stress Scale demonstrated satisfactory levels of internal reliability (.83), and test-retest reliability (.81).

### **2.3 The General Health Questionnaire (GHQ-12)**

The General Health Questionnaire (GHQ-12) was used to measure psychological distress. It was originally developed by Goldberg in 1970 (3) and is a widely used tool in primary care to screen for psychological distress and psychiatric morbidity. Its use as screening instrument is well established (4) and is validated in Pakistan (5). Each question has 4 possible responses, i.e. less than usual, no more than usual, rather more than usual, or much more than usual. Cut off point for high scoring was set at a positive response (much more than usual) to at-least 3 of the 12 items.

### **2.4 Brief COPE**

The Brief COPE, originally developed by Carver (1997) and translated into Urdu by Akhtar (2005), was used to identify the coping strategies used by parents. Brief COPE is a brief form of COPE Inventory (Carver et al., 1989) consisting of 28 items, categorized into 14 subscales (Self distraction, Active coping, Denial, Substance abuse, Use of emotional support, Use of instrumental support, Behavioral disengagement, Venting, Positive reframing, Planning, Humor, Acceptance, Religion, Self blame). Items are arranged in a 4-point Likert format (1= Never, 2= Very less, 3= Sometimes and 4= A lot). The items are summed for each subsection separately to get a total score on all 14 categories. The high score on each subscale indicate more use of that particular coping strategy and low score indicate less use of that coping strategy. The respondents' demographic and clinical characteristics were also recorded on history taking proforma. Data was analyzed through SPSS-14. Descriptive statistics were used to describe the data. Independent Samples t-test was used to compare scores between different groups. P-value < 0.05 was considered as significant.

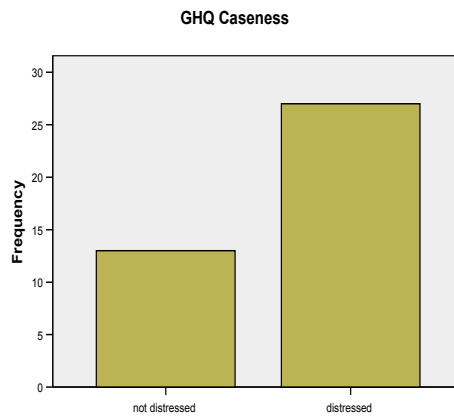


Fig. 1: Graph for GHQ Distressed\Not distressed

### 3. Results

A total of 40 parents, 17 fathers & 23 mothers were included in the study. Age of the parents ranged from 30-50 years. All the parents (40/40) were found to have severe parental stress. Psychological distress was observed in 27 (67.5%) parents as shown in figure 1. Different coping strategies were employed by parents. Most commonly used coping strategies were Active coping (97.5%), Planning (95%), Acceptance (92.5%), Religion (92.5%), self-blame (92.5%), Use of instrumental support (90%), Positive reframing (87.5%), and Self-Distraction (82.5%). Others include Use of emotional support (73%), Venting (70%), Behavioral disengagement (62.5%) and Denial (60%). Least used coping strategies include humor (15%), and substance use (7.5%). Details are shown in table 1. Significant gender differences were observed on GHQ. Mothers were found to have more distress than fathers. No differences were observed on parental Stress Scale (PSS). Significant differences were found on coping strategies of Denial ( $p < 0.01$ ) and Behavioral disengagement ( $p < 0.05$ ). Both coping strategies were more prevalent in fathers. Details are shown in table-1 & 2.

Table 1: Mean, SD and t-value of Parents (Fathers and Mothers) of Thalassemic Patients on the total scores of GHQ and PSS (N = 40)

Scales	Gender (Fathers) (n = 17)		Gender (Mothers) (n = 23)		t
	M	SD	M	SD	
GHQ)	12.47	4.571	16.57	6.381	-2.250*
PSS	66.24	6.350	65.74	11.017	.166

$df = 38$ , \* $p < .05$

Table 2: Mean, SD and t-value of Parents (Fathers and Mothers) of Thalassemic Patients on the subscales of Brief COPE (N = 40)

Subscales	Gender (Fathers) (n = 17)		Gender (Mothers) (n = 23)		t
	M	SD	M	SD	
Self-distracton	6.06	1.435	5.13	1.866	1.710
Active Coping	7.59	.712	7.39	1.270	.575
Denial	5.29	.849	4.17	1.557	2.6818**
Substance use	2.47	1.375	21.45	2.22	.718
Use of emotional support	5.41	1.278	4.57	2.107	1.467
Use of instrumental support	6.35	1.618	5.96	1.942	.684
Behavioral disengagement	3.65	2.120	4.96	1.894	-2.055*
Venting	4.65	1.656	4.78	1.682	-.237

Positive-reframing	6.47	1.908	6.87	1.817	-.672
Planning	7.12	1.576	7.22	1.380	-.213
Humor	2.82	1.629	2.43	1.472	.789
Acceptance	6.00	1.803	6.43	1.376	-.866
Religion	7.41	1.583	7.30	1.521	.217
Self-blame	6.41	1.326	5.70	1.636	1.480

*df = 38, \*\*p < .01, \*p < .05, p = n.s*

## 4. Discussion

Thalassemic children are individuals who suffer from a severe chronic hemolytic anemia requiring transfusions as treatment for their survival. This chronic illness is a source of stress for the parents and the rest of the family. Such situation results in the existence of various types of emotional reactions and behavioral patterns in the family, which affects the relationships of family members amongst each other and with their surroundings. Chronic illness of a child affects the parents at: cognitive levels, emotional level and their daily routine(6). In the present study psychological distress and coping strategies among parents of  $\beta$ -thalassemic patients showed that all the parents of these thalassemic patients experienced severe parental stress however, psychological distress was reported by 27 (67.5%) parents (Figure-1). Beta thalassaemia is an unending illness that can lead to excessive psychological burden to the patients and their families. Many studies done by Rao P, Pradhan PV have reported that the frequency of psychopathological disorders is higher in parents of children with chronic and disabling diseases (thalassemia) as compared to the normal population(7). It is reported by Deepika Shaligram, that fifty seven percent of the caregivers had psychiatric problems and Quality of Life was affected in 50%. Another study revealed that parents of thalassemic patients experienced higher degrees of distressfulness when compared with parents of normal children (8). This frequency of psychological distress leading to parental stress is higher due to the multiple problems which parents have to face while going through the rigorous and painful treatment procedures of thalassemia. They have to face many concerns like the psychosocial adjustment of the child, financial problems, provision of treatment, travelling and other social problems.

An additional goal of the present study was to evaluate the coping strategies of parents. For this purpose COPE Inventory was used which has fourteen types of coping strategies. Different coping strategies were employed by parents. Most frequently used coping strategies were Active coping (97.5%), Planning (95%), Acceptance (92.5%), Religion (92.5%), self-blame (92.5%), Use of instrumental support (90%), Positive reframing (87.5%), and Self-Distracton (82.5%). Others include Use of emotional support (73%), Venting (70%), Behavioral disengagement (62.5%) and Denial (60%). Least used coping strategies were humor (15%), and substance use (7.5%). Significant differences were found on coping strategies of Denial ( $p < 0.01$ ) and Behavioral disengagement ( $p < 0.05$ ). Both coping strategies were more prevalent in fathers. As fathers were found to have difficulty in accepting their child's disease and denied it completely. This behavior made the fathers to be overprotected about their child which inturn effected the psychosocial development of the child. Coping strategy of denial was associated with the guilt of the parents, and any negative remarks from the environment played a significant role to enhance such behavior. Studies carried out by Dr. Grattan have shown that patients who show behavioral disengage are not realizing their loss and are not making any efforts to improve their condition. Such behavior of fathers hamper the treatment of their children(9). The awareness of the illness has been suggested as a possible factor influencing both the compliance with treatment and the quality of life of Parents. A previous study done by Aydinok Y found that awareness of the illness by the thalassemic children and their family made them more compliant with the therapy, as they were provided with the psychological support they needed to treat their depression, obsession, paranoia, and hostility(10).

## 5. Recommendations

A psychosocial support aimed at reducing emotional distress of the parents, and strengthening their coping strategies for a better integration in daily life, is therefore necessary.

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