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# Psychological Distress in Parents of Children Diagnosed with and Without Thalassemia

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**Abstract**

**OBJECTIVE**: The purpose of present research was to investigate the difference in distress, inclusive of level of depression, anxiety, and stress of those parents whose children are suffering from thalassemia and parents whose children are not suffering from thalassemia.

**HYPOTHES:** It was hypothesized that: parents of children with thalassemia would score higher on the variable of psychological distress; a) Depression, b) Anxiety, and c) stress as compared to the parents of children without thalassemia

**PARTICIPANTS:** The entire sample was consisted of 120 parents (60 with thalassemia & 60 without thalassemia, both groups consist of 30 mother and 30 father parents. The entire sample of parents of children with thalassemia was drawn from Fatimid Foundation located in the city of Karachi, Pakistan and without thalassemia from a private school located near Fatimid foundation. Data of parents of children without thalassemia was collected from parents of normal school locate near the area of the hospital.

**MEASURES:** Depression, Stress and Anxiety Scale (DASS, Lovibond & Lovibond, 1993), Urdu version by Husain W, Gulzar AJIotD, Anxiety,2020 consist of 42 items rated on four-point Likert scale and based on the depression and anxiety models. It measures the negative emotional symptoms of a person.

**PROCEDURE:** After getting signature of parents on Introduction to participant and Informed consent form the data was collected by the administration of demographic Information form and Depression, Stress and Anxiety Scale (DASS)

Parents of patients of thalassemia were approached through hospital and normal school of Karachi where patients and parents came along with their parents for the purpose of their treatment. They were called one by one by the researcher through their intake files. Data was collected by interviewing them on the measure of Depression Stress and Anxiety Scale (DASS) 42 item scale based on the depression

and anxiety models. Whereas the normal children parents' data was collected to a nearby normal school with consideration of all ethical concerns.
**Staistical Analysis**: In order to interpret and convert the data in statistical terminology descriptive statistics were computed as well as t' test as Inferential statistics was applied. Results indicate that the hypothesis was partially proved as parents of children with thalassemia, were significantly higher on the level of depression and anxiety, but there appeared insignificant difference between both the groups on the variable of stress.
**Conclusion:** It was concluded that depression and anxiety were significantly high in parents of thalassemia however there was no difference in the level of stress both the groups.

## Introduction

Thalassemia is an inherited blood disorder in which the blood carries deficient amount of hemoglobin, which leads to destruction of red blood cells hence the body becomes anemic and requires continuous blood transfusion [1]. Despite the rigorous provision of a series of complicated, painful, and wearisome yet standard quality treatment in thalassemia, only a few patients reach adult life[2] and 85-90% of children and adolescents have maximum life expectancy of 20 years of age[3] only. According to ratings of World Health Organizations (WHO), thalassemia turned out to be the most prevalent genetic blood disorder having roots in more than 60 countries of the world in the form of up to 150 million carrier population[4.] Pakistan also has a highest number of thalassemic patients with an estimated average birth rate of 4000 children per year affected by transfusion dependent beta-thalassemia[5.]

This chronic illness does not only adds in financial burden of the family but also aids in psychosocial stressors that often leads to psychological distress which is defined as a state of emotional suffering represented via symptoms of depression, anxiety, and stress[6.] Along with children who suffer from thalassemia, their families especially primary caregivers and parents also experience psychological and social consequences the most due to clinical burden[7.] Parents of children with thalassemia are also unable to feel the joy of having a child, as they constantly face disease related concerns such as low life expectancy of their child, short stature, recurrent checkups, frequent blood transfusion process, and associated illnesses like heart diseases, bone deformities, and diabetes[8.]

Results of a previous comparative study in Iran showed that mothers who had children with physical complaints or chronic ailments reported relatively higher number of psychological distress and psychiatric disorders such as depression, anxiety, phobia, paranoia, interpersonal sensitivity, obsessive-compulsive disorder, and physical complaints than the mothers who have normal children[9.] Hence parents of children with thalassemia are also found to be more burdened and under-stress due to the chronicity of illness[1]

Previous researches have also shown a significant relation between psychological distress in parents and severity of chronic illness of children thus the more severe is illness in child the greater would-be level of depression, anxiety, stress or other psychiatric illness in parents[11.]

Adding on, parents of children with thalassemia are more prone to psychological distress, due to their inability to cope with the situation and it provokes feelings of guilt, hopelessness, and anxiety[12.] Thus, this study aims to explore relationship between psychological distress in parents with or without thalassemia in order to find out the impact of this chronic ailment on Pakistani parents who have children suffering from this life-threatening disorder.

## METHODS

### Participants

120 parents were approached for this study. Half of the sample comprised of the parent of children with thalassemia (21 males and 39 females) and half (34 males and 26 females) were parents of children without thalassemia. The overall mean age was 41.9 ± 11.9 years.

### Description of Measures:

Psychological distress in terms of depression, anxiety, and stress was measured through Depression, Anxiety Stress Scale (DASS) Urdu version. It is a self-report 4-point Likert scale and composed of three subscales: Depression (DASS-D), Anxiety (DASS-A), and Stress (DASS-S). The DASS-42 scale measures each of the three mental health conditions, over the past week, through seven items. Responses on each item range from 0 (*did not apply to me at all*) to 3 (*applied to me very much*). The internal consistency reliability coefficients for the overall scale and its subscales for depression, anxiety and stress were .86, .74 and .86 respectively. The analysis for construct validity of U-DASS-42 revealed significant positive correlation between U-DASS-42 and its subscales i.e. depression ($r = .91$, $p < .001$) anxiety ($r = .97$, $p < .005$), and stress ($r = .92$, $p < .001$).[13]

### Procedure

Permission was sought from the head of the particular hospital where children used to come in order to sought treatment for thalassemia. Purpose of the study and its implications were described briefly to the management. The sample of present research consisted of 120 parents and it was drawn from one hospital. The age of the participants was 18 to 50 years. Informed consent was taken from participants, and they were being told regarding voluntary participation along with their right to withdraw anytime. Both of the questionnaires were administered individually, including inform consent, and personal demographic sheet addressing name, age number of children, and year of diagnosis. Depression, Stress and Anxiety inventory was administered afterwards. Parents were also debriefed regarding the purpose of this study and were thanked for their participation. Participants were then being assured about confidentiality and utilization of data for the research purpose only.

## RESULTS Table 1: Demographic characteristics of study parents

| | | Frequency | Percentage |
|---|---|---|---|
| Age (mean ± SD) | 41.9 ± 11.9 | | |
| year of diagnosis (mean ± SD) | 12.1 ± 5.44 | | |
| | | | |
| Education | Nil | 33 | 27.5 |
| | Primary | 20 | 16.7 |
| | Matric | 25 | 20.8 |
| | Bachelor | 22 | 18.3 |
| | Masters | 20 | 16.7 |
| | | | |

| | | | |
|---|---|---|---|
| Marital Status | Married | 117 | 97.7 |
| | Widowed | 3 | 2.5 |
| | | | |
| Monthly Income | < 25000 | 63 | 52.5 |
| | 25000-50000 | 29 | 24.2 |
| | 51000-75000 | 7 | 5.8 |
| | > 75000 | 21 | 17.5 |

In this research study, there were 60 parents (male 21 and female 39) whose patients suffered from thalassemia and 60 parents (male 34 and female 26) with non-thalassemia children. Table 1 shows demographic characteristics of study parents, mean age of parents was 41.9 ± 11.9 and mean year of thalassemia diagnosis was 12.1 ± 5.44. Just more than one-fourth of the parents were illiterate, next prominent education was matric (20.8%) whereas proportions of primary, bachelor and masters did not differ notably. There were only 2.5% participants widowed and more than half of the parents' monthly income were less than 25000/month.

**Table 2: Frequency distribution of depression, anxiety and stress among parent with thalassemia and non-thalassemia children**

| Variables | | Thalassemia | Non-Thalassemia |
|---|---|---|---|
| Depression | No | 4 (6.7%) | 44 (73.3%) |
| | Mild | 7 (11.7%) | 8 (13.3%) |
| | Moderate | 9 (15%) | 4 (6.7%) |
| | Severe | 11 (18.3%) | 4 (6.7%) |
| | Extremely severe | 29 (48.3%) | 0 (0%) |
| Anxiety | No | 4 (6.7%) | 43 (71.7%) |
| | Mild | 5 (8.3%) | 8 (13.3%) |
| | Moderate | 18 (30%) | 8 (13.3%) |
| | Severe | 0 (0%) | 0 (0%) |
| | Extremely severe | 33 (55%) | 1 (1.7) |
| Stress | No | 5 (8.3%) | 35 (58.3%) |
| | Mild | 11 (18.3%) | 15 (25%) |
| | Moderate | 5 (8.3%) | 7 (11.7%) |
| | Severe | 21 (35%) | 3 (5%) |
| | Extremely severe | 18 (30%) | 0 (0%) |

Table 2 represents frequency distribution of levels of depression, anxiety and stress among parents with thalassemia and non-thalassemia children. Among parents with

thalassemia children the most prominent level of depression is extremely sever (48.3%) whereas among parents with non-thalassemia children, three-fourth did not have any depression. Similar trend was also observed for anxiety, majority of the parents with thalassemia children had extremely sever anxiety whereas no anxiety was found among most of parents with non-thalassemia children. Stress levels, severe and extremely sever were prominent among thalassemia groups and no stress was among non-thalassemia group. Statistical associations of depression, anxiety and stress were also identified through chi-square test. P-value in above table 3 show that there were statistical significant associations of depression, anxiety and stress with grouping variable (thalassemia and non-thalassemia).

**Table 3 Difference between Parents of Children with and without thalassemia on variables of Psychological Distress**

| Variable | Groups | N | M | SD | t' | Df | Sig |
|---|---|---|---|---|---|---|---|
| | | | | | | | |
| Depression | With thalassemia | 60 | 26.633 | 11.483 | 12.003 | 118 | .000** |
| | Without | 60 | 6.516 | 6.054 | | | |
| | | | | | | | |
| Anxiety | With | 60 | 22.883 | 9.55642 | 12.779 | 118 | .000** |
| | Without | 60 | 5.683 | 4.16804 | | | |
| | | | | | | | |
| Stress | With | 60 | 27.883 | 9.0048 | 10.483 | 118 | .079 |
| | Without | 60 | 12.350 | 7.1160 | | | |

* *p*-value ≤ 0.05 considered as significant (t-test). **= p < .001

Table 4 illustrates that the scores of parents of children with thalassemia (Depression M=26.633, SD=11.483, Anxiety M=22.883, SD=9.55642, Stress M=27.883, SD=9.0048) on the variable of psychological distress was found to be higher as compared to the scores of caregivers of children without thalassemia (depression M=6.516, SD=6.054, Anxiety M=5.683, SD=4.16804, Stress M=12.350, SD=7.1160) with a statistical significance proven through a t value of 12.003, 12.779, 10.483 and p value of .000, .000, respectively however stress p value is insignificant .**079**.

## DISCUSSION

Thalassemia is a chronic disease, and it reflects burden on families which is evident by psychological stressors and mental health impacts on caregivers especially on parents. The purpose of the current study was to compare parents of children with and without thalassemia. It was found that majority of the parents were experiencing psychological distress including depression, stress and anxiety as compared to children of parent without thalassemia which might have happened due to the chronicity and pain inflicting treatment of this disorder. Results are consistent with previous findings that severity level of mental health related issues such as depression, anxiety, and stress in parents is directly proportional to the severity level of disorder of their ward.[14]

According to the result of this study, there was a statistically significant difference between level of depression experienced by parent of children with thalassemia (26.6%) as compared to non thalassemic group (6.51%). Parents also scored high on extremely

severe depression (48.3%) as compared to normal ones that three fourth did not have any depression. These results are also congruent with previous study in which the level of depression in parents of children with thalassemia was reported to be 51%.[15] Another study carried out in Bahawalpur also showed similar results and the level of depression was found to be 71% however they did not compare the level of mental health problems with parents of non-thalassaemic children which laid foundation for this study. [16]
Moreso, data has also shown that besides depression, anxiety also prevails in caregivers of children having thalassemia which might happen due to continuous and expensive blood transfusion treatment, frequent visits to hospitals, and the uncertainty attached with the child's future hence according to Canatan et al, nearly 82% of parental anxiety was reported in Turkish parents having children suffering from this ingenious blood disorder[17.] These results are consistent with Pakistani context as well as results of this study has shown that there was a significant difference between level of anxiety experienced by parents of children with thalassemia (22.8%) and it was significantly higher than that experienced by parents (5.6%) whose children were non-thalassaemic. With ongoing illness there is an increase in stressors experienced by caregivers or parents whose children have life threatening illness. These stressors vary as the diagnosis, blood transfusions, and illness went on, increasing health care need of the child[18,] which could be the reason behind higher stress level in parents of children having thalassemia as compared to their normal counterparts. This study also showed significantly higher stress level (27.8%) in parents taking care of thalassaemic children than the stress level (12%) in parents whose children did not have blood disorder. Thus, parents of thalassaemic children are reportedly more exhausted, stressed, and scared due to the insecurity attached with the future of their child[19.]
Furthermore, literature also provided the support for overall findings of present study which indicates negative effects on mental health parents who handle chronic illnesses of their children. Hospitalization and death rate is higher among children of parent with thalassemia which shows comorbidity with depression and stress. Lack of definitive cure for thalassemia and blood transfusion being the only choice creates mental and emotional burden on not only children affected by this chronic illness, but also makes their parents and caregivers prone towards mental health poblems[19]

## CONCLUSION

The present study explored the relationship between depression, stress and anxiety among parent of children with and without thalassemia. Overall findings of the present research suggest that parent of children with thalassemia have more mental health problems as compared to those parents whose children are not suffering from any disorder. This study has varied implications such as educational, social and clinical because of the high prevalence of anxiety depression and stress. It is highly recommended that the mental health screening procedures could be used in hospitals in order to help parent to overcome their anxieties and stress related issues. Parents should properly educate about the disease and have to develop better understanding how to deal with it. Mental health practitioner can also serve to help them for a better community.

## RECOMMENDATION & IMPLICATIONS

The findings of this study suggest that parents of children with thalassemia experience greater psychological distress than parents of children without the condition, highlighting the need for targeted psychosocial support. Routine psychological screening and counselling services should be integrated into thalassemia care to identify and address parental stress, anxiety, and depression at an early stage. Providing parental education, coping skills training, and access to peer support groups may help reduce emotional burden and improve adjustment. Clinically, a family-cantered care approach is essential, as parental mental well-being directly influences the child's treatment

adherence and overall health outcomes. At the policy and public health levels, strengthening mental health services, financial support systems, and community awareness programs can play a crucial role in improving the quality of life of families affected by thalassemia.

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