

# PSYCHOLOGICAL BURDEN IN $\beta$ -THALASSEMIA AFFECTED FAMILIES

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## ABSTRACT

**Objective:** Assessing the psychological burden on families affected by Thalassaemia may face, controlling for cultural and social setup.

**Methodology:** A cross-sectional survey is done with the help of structured interviews and questionnaires. Self-designed questionnaire is used to determine the demographics of the patients, whereas questionnaire developed by Ratip and Modell (1996) used to gauge the psychological pressure the thalassaemia affected family faces. The survey was conducted in different health centers of Peshawar that specialize in providing medical facilities to patients suffering from blood disorders. Logistic Regression and Chi Square test of Association used to arrive at results.

**Results:** The results revealed that the parents of a Thalassaemic patient face problems with social interaction. They are anxious about their child's health, and face isolation. However, due to cultural setup their family supports them but the disease of the child does not affect their relationship with other children and spouse.

**Conclusion:** Cultural and social setup affects the magnitude of the psychological burden inflicted on a Thalassaemia affected family. Families living in rural areas found more disturbed. The effect of different factors on social life differs for male and female patients.

**Key Words:** Culture, Psychological burden, Financial burden, Thalassaemia

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## INTRODUCTION

The high frequency of treatment procedures of thalassaemia patients, low life expectancy, and expected future complications, increase psychological pressure on parents and patients themselves<sup>1</sup>. Psychological pressure may be due to deteriorating health of patient, inability of parents to afford treatment, medication, blood transfusion or patient's hospitalization<sup>2</sup>.

One can hypothesize that in an extended family setup where parents can rely on other family members for support, may not be overly burdened by the diseases<sup>3,4</sup>. However, the same factor can turn against them for having increased social responsibilities in joint family system<sup>5</sup>.

Cultural and health care setup in Pakistan varies from many other countries. In this part of the world, families with genetic diseases are characterized with stigmatization<sup>6</sup> with inadequate health care options<sup>7</sup>. This may increase the overall psychological burden on the family. This study was aimed with examining the psychological burden asserted by Thalassaemia on families and the ef-

fect of cultural norms and family setup on it.

## METHODOLOGY

Population for this study consists of those families which have affected by Thalassaemia major in KP and FATA i.e. having at least one affected child, and sample is drawn from the same population. Therefore, only those health centers are approached that provide blood transfusion facility to thalassaemia patients. A structured questionnaire comprised of demographics questions measuring the psychological burden faced by the parents and the patient himself / herself was designed by Ratip and Modell<sup>8</sup>, 1996 is adopted. Due the low literacy rate in Khyber Pakhtunkhwa, the respondents were interviewed in their native language- Urdu and Pashto. As a result, a total of 360 families were interviewed; 58% of the families had male patients while 42% of the families were supporting a female patient. The variables that add to the psychological burden of parents of Thalassaemic patients were social life, anxiety, isolation, relationship with spouse and children<sup>9</sup>. As identified in literature, the set of independent variables and confounding variables

for better understanding of the phenomena under study were included in the analysis. These variables are constant prescription; proper arrangement of medication; availability of blood; mode of financing for treatment and child hospitalization. Adopting the quantitative approach, the above-mentioned variables were quantified and analyzed through binary logistic regression. The details of the quantification are given in Appendix. A chi square test of association was run to assess the factors affecting the social life of the parents. These variables are binary categorical in nature.

## RESULTS

The significant odds ratio for family type shows that the odds joint family, the parent's social life is affected is 1.4816 more than that of the parents in nuclear family (Table I). Another variable, locality was considered for the fact that the social life in rural areas and urban areas are entirely different and hence the impact in these two areas was assumed to be different. Not only this but the fact that people from rural areas have to manage transportation, and lodgings in case of hospitalization, also differs the situation for the two localities. The chi square test showed that the association between the locality and the social life is highly significant. The odds ratio 2.303 showed that the odds the social life will be affected is 2.303 more for the parents living in urban areas than that of the parents living in rural areas.

After the preliminary analysis, Social life is regressed on a set of explanatory variables. Results are given in the following Table II.

The odds that the unavailability of the blood, absence of constant prescription, no proper arrangement of medication and if the child is never hospitalized will affect the social life of the parents is 3.78 (constant in the model given as  $e^{1.331}$ ). The odds ratio of blood availability 0.486 indicates that the odds that the social life will be affected have reduced. That is the odds are 2.05 more in case of the blood unavailability that the social life will be affected. Similarly if the medication cannot be properly arranged the odds that the social life will be affected is 1.68 more than if the medication is readily available. The hospitalization of the child increases the odds by 1.591 as compared to no hospitalization. The odds for the parents of a child under constant prescrip-

tion are increased by 1.49 as compared to those who are not administered. One can easily conclude from these analyses that the social life of a thalassemics parents found significantly affected by these factors.

### Supplementary Findings:

Anxiety was another variable used as an indicator for psychological burden on parents. The data showed that 96% of the parents were anxious about their children and disease, which is a significant number. On asking about their biggest worry concerning their children, most of the parents respond for the unavailability of the blood, life and health of the child, and financing for the treatment. Parents showed concern about their children's marriage as well. Some parents informed that they are worry only about the health of their child and whether it will ever be cured or not.

The research also tried to inquire the relationship between spouse and that of parents with other children was affected, in addition to feelings like isolation, guilt, denial experienced by the parents of the patients. 83% parents said that they often talk about the disease to others. This may suggest that they concern about their children's health. 58% parents claim that they trust their spouse when they need help and can discuss their s problems to relieve themselves from the psychological burden. The disease however has not affected their relationship with their spouse and other children. Depression and anxiety burden also reported around 94% (unhappy) initially when they came to know about the disease.

As reported by Shaligamet al<sup>10</sup>, sex of the child also plays an important role while studying the psychological disorder of the parents. The effect of different factor on social life differs for male and female patients that are a suggestive signal for gender discrimination. Parents showed that their social life being affected due to child disease and the factors like the mode of financing the treatment and child hospitalization, found not same for the male patient.

The study being conducted in an Islamic country, the effect of religion is taken into account. The trouble is increased of arranging for blood, in the holy month of Ramadhan, in which people normally avoid blood donation. Not only this but parents face difficulty arranging

**Table 1: Effect of Gender, family type, locality and number of children on Social life of parents**

Variable	Chi-Square P-Value	Odds Ratio	P-value
Patient Gender	0.216	1.319	0.216
Family Type	0.075*	1.486	0.075
Locality	0.015**	2.303	0.017
Number of Children	0.115	0.626	0.118

\* Significant at 10%

\*\*significant at 5%

**Table 2: Logistic Regression Analysis**

independent Variables	B	S.E.	Wald	Df	Sig.	Exp(B)
Blood Availability	-.722	.422	2.930	1	.087*	.486
Constant Prescription	-.399	.236	2.868	1	.090*	.671
Medication arrangement	-.522	.288	3.296	1	.069*	.593
Child Hospitalized	.465	.257	3.270	1	.071*	1.591
Constant	1.331	.456	8.515	1	.004***	3.786

Significant at 10% \*\* significant at 5% \*\*\*significant at 1%

for blood even during the official holidays. Some parents were worried about their family extension and said that they are worried if the disease will be diagnosed in their other children, as it will result in the increasing the burden of the disease on them. As reported earlier by other studies conducted in India and Pakistan<sup>2,4,5,7</sup>, the disease has an ignorable effect on the family relations. Their relationship with spouse and other children in the family do not suffer because of the child's disease. It can be easily concluded that the amount of psychological pressure that a family has to face may vary with the cultural setup prevalent in the region. This should be taken into account while planning for prevention and intervention.

## DISCUSSION

The results showed that in joint family system one needs to give more time to the other family members as compared to a nuclear family where less responsibility in a household may be required and due to the fact that the patients has to be taken care of, the social life of the parents in joint families is more effected. Not only the family type but also the residents of urban and rural areas reported different experiences. Those who live in urban areas have a busy and active social life compared to rural residents and the social life of the urban area residents are more likely to disturbed by such events. The gender of the patient and number of children in the family however did not demonstrate any significant association.

Moreover the results showed that thalassemia is not the only concern for the parents but other associated disease with thalassemia such as heart diseases also cause them anxiety. The fear that the child may not survive for long and is in pain causes them stress. Cost of treatment also reported by Canatan<sup>11</sup>, unavailability of blood, hospitalization and traveling to the health centers is adding more to the anxiety of the parents. Most of them confessed crying about the situation and having disturbed sleeping patterns. The fear that others child may also be diagnosed for the disease add up to their psychological burden. These findings coincide with Ali's<sup>12</sup> study which reported that high level of anxiety is caused by the negative thoughts, guilt, inability

to cope with painful situations and imbalanced relationships with other family members increases isolation. The fear factor may be caused by lack of knowledge about prevention as well as lack of resources for pre natal test increasing their burden further. It is concluded that Cultural and social setup affects the magnitude of the psychological burden inflicted on a thalassemia affected family. Families living in rural areas are more disturbed because of the unavailability of blood. The effect of different factors on social life differs for male and female patients respectively.

## CONCLUSION

Cultural and social setup affects the magnitude of the psychological burden inflicted on a Thalassemia affected family. Families living in rural areas found more disturbed. The effect of different factors on social life differs for male and female patients.

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**CONTRIBUTORS**

ZZ conceived the idea, planned the study and drafted the manuscript. SW and BH helped acquisition of data. SZ and QZ drafted and critically revised the manuscript. MI acquisition of data and did statistical analysis. All authors contributed significantly to the submitted manuscript.

**Appendix** The following table represents the values assigned to each variable according to their nature, for the purpose of analysis.

	Value Assigned = 0 (zero)	Value Assigned = 1 (one)
<b>Dependent Variable</b>		
Effect on Social Life	Not at all	A little + A lot
<b>Independent Variables</b>		
Constant Prescription	No	Yes
Arrange for medication	No	Yes
Availability of blood	No	Yes
Treatment Financing	Family Support / Government Support / Donor Support	Self Finance
Child hospitalized	No	Yes
<b>Control Variables</b>		
Family Type	Nuclear Family	Joint Family
Patient Gender	Female	Male
Locality	Rural	Urban
Children in Family	One or two	More than two