**ORIGINAL ARTICLE**

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**PSYCHO-SOCIAL AND ECONOMIC IMPACT OF THALASSEMA MAJOR ON PATIENTS' FAMILIES**

KAMRAN ISHFAQ¹, SALMAN BIN NAEEM², TANVEER AHMAD³, SAFIA ZAINAB⁴

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**ABSTRACT**

**OBJECTIVES:** To identify the psycho-social and economic impact of Thalassemia major on patients' families.

**STUDY DESIGN:** A cross sectional study.

**PLACE AND DURATION:** The study was conducted in the Thalassemia Centre, The Children's Hospital & the Institute of Child Health Multan (CH&ICH) from 1st March 2015 to 28th July 2015.

**METHODOLOGY:** The data was collected from the 500 registered Thalassemia major patients' parents who visited Thalassemia Centre of the Children's Hospital & the Institute of Child Health Multan (CH&ICH). The structured interview was used as a tool for data collection with the help of convenient sampling. Written and verbal informed consent was obtained from the parents. Data was analyzed and interpreted by using the Statistical Package for Social Sciences (SPSS) 20.0 version software. The structured interview was discussed with two senior doctors (>8 years' experience) working in the Thalassemia Centers and public health institutions. It was revised to incorporate the recommendations and improvements. Descriptive and inferential statistics were applied to analyze the data which include: frequency, percent, mean, standard deviation.

**RESULTS:** A total number of 500 thalassemia major patients' parents were recruited in this study who visited to the Thalassemia Centre, The Children’s Hospital & the Institute of Child Health Multan for the treatment of their children. The majority of the respondents were mothers (76.2%) while (23.8%) of the respondents were fathers. Of the 500 respondents majority of the parents were belonging to the Saraiki background (43.0%), Urdu (21.6%), Balouchi (19.0%), Sindhi (0.6%), Pathan (5.8%) and Punjabi (5.8%). Grater part of the respondents were unemployed (31.6%), while (14.0%) were businessmen, (24.0%) were private jobs, (4.0%) were doing Government Jobs and immense part of the respondents were laborers (26.4%). The monthly income of about (59.12 %) of the respondents was below PKR 10,000.

**CONCLUSIONS:** A substantial number of parents have psycho-social and economic problems due to the thalassemia disease of their child. The study summarized that the parents of thalassemia major patients and the general public should be sensitized in this regard. Thalassemia prevention program should be introduced to minimize the burden of Thalassemia major patients' parents.

**KEYWORDS:** Psycho-social, Economic, Impact, Thalassemia Major, Patients, Families.

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**INTRODUCTION**

Thalassemia is an inherited blood disorder which is passed from parents to their children in which abnormal hemoglobin born in the bodies. This disorder results in extreme destruction of red blood cells and there is no effective treatment. Thalassemia major patients dependent on the regular blood transfusions throughout life. In Pakistan, thalassemia is seen in almost all parts of the country. It is an estimated that about 9000 beta Thalassemia children are born every year in Pakistan. Further, it's a serious disease causing severe anemia. There is no Thalassemia disease registry in Pakistan. Most recent data shows that national carrier rates at 5-7 percent (approximately 10 million). Due to cultural and the religious scenario in Pakistan premarital screening and prenatal diagnosis are not common among the families. Thalassemia major patients faced other associated problems like heart, liver, endocrine and skin, glands. The concept of termination of pregnancy is an ethical issue in Pakistan. The only cure of Thalassemia major is bone marrow transplant, which is beyond the reach of maximum families in this Country. Approximately Thalassemia major patients required 8000-10000 PK rupees medicines per month and they are dependent on the regular transfusion. In the developing countries like Pakistan, the major reason of thalassemic deaths are due to non compliance of treatment because of psychosocial and economic factors.

The best way to reduce the burden of thalassemia disease is prevention. There are different strategies to prevent the Thalassemia, which include population screening, parental education, prenatal diagnosis and genetic counseling. The Countries like Turkey and Cyprus have implemented the strategy of stopping birth of new Thalassemia children. In Iran, premarital screening, genetic counseling has been made compulsory by the Government. This strategy has produced good results for the prevention of Thalassemia in their Country. A limited number of studies have been carried out in Pakistan, but these studies reported that Thalassemia major disease not only affect the child health, but also devastating the psychological, social and economic burden for the families. But previously no study has been carried out in the population of Southern Punjab, Pakistan, therefore this study is carried out to fill the gaps in the literature and to contribute to it.
For the determination of thalassemia carrier status, parental screening is very important to help the couple, but unfortunately genetic counseling tests are still not a common practice in Pakistan.

The study will help policy makers, philanthropist, social worker, and society member and health professionals understand the miseries of Thalassemia major on patients’ families. The present study aimed to identify the psycho-social and economic impact of thalassemia major patients and their families.

**METHODOLOGY**

The study was conducted at the Thalassemia Centre of the Children’s Hospital & the Institute of Child Health Multan, Pakistan during the period of 1st March 2015 to 28th July 2015. A total of 500 Thalassemia major patients’ parents were interviewed with the help of convenient sampling. Prior to conducting interview schedule, written and verbally consents were obtained from the subjects. Ethical approval was obtained from the Ethical Committee of The Children’s Hospital & the Institute of Child Health (CH&ICH) Multan. Thalassemia major patients’ parents were recruited and the other types of blood disorder patients’ parents were excluded from the study such as A-plastic anemia, hemophilia, Acute Lymphoblastic Leukemia. The data were analyzed statistically by using the SPSS (Statistical Package for Social Sciences) version 20 which include percentage, frequency distribution, mean and standard deviation.

**RESULTS**

Figure - 1. Showed the distribution of respondents by their child’s frequency of blood transfusion. Among the total respondents, 83(16.6%) of the respondents weekly visited to the Thalassemia Centers for the purpose of their children transfusion while 214(42.8%) of the respondents visited Thalassemia centers after fifteen days. 168(33.6%) of the respondents visited for their children transfusion on a monthly basis. Only 35(7.0%) respondents visited to the Thalassemia centers more than monthly.

Figure - 2 described the distribution of respondents by their marriage type. Of the total respondents, 306(61.2%) were married to their first cousins, 91(18.2%) of the respondents were married to their second cousins, 34(6.8%) of the respondents married in distance relatives and 69(13.8%) of the respondents married out of family. It is observed that 306(61.2%) couples married endogamous with 1st cousins. It further shows that mostly the marriage with the first cousin leads to the Thalassemia Major in the family.

Respondents were asked multiple statements regarding psycho-social and economic impact of the disease. Majority of the respondents 'some extent' feel that their life is unsuccessful and messed-up because of a child disease ($\mu=3.10$). They 'some extent' feel hesitation while talking about the disease to others ($\mu=2.70$). However, they feel mental stress 'not at all' because of the child disease ($\mu=1.05$). They 'some extent' participate in different family gathering ($\mu=3.39$) and were having 'not at all' homelessness feelings because of a child disease ($\mu=1.42$). They 'some extent' receive assistance from relatives in time of need ($\mu=3.46$). However, a child disease effects conjugal relationship 'to a great extent' ($\mu=3.50$). But they feel financial burden 'not at all' because of a child treatment ($\mu=1.01$) (Table 2).

| Table – 1: DEMOGRAPHIC CHARACTERISTICS OF THE PARENTS OF THALASSEMIA CHILDREN (n=500) |
| Variables | Frequency (%) | Variables | Frequency (%) |
| Gender | | Education | |
| Male | 119(23.8) | Literate | 234(46.8) |
| Female | 381(76.2) | Illiterate | 266(53.2) |
| Age | | Residential Area |
| 15-30 | 25(5.0) | Rural | 244(48.8) |
| 31-40 | 350(70.0) | Urban | 256(51.2) |
| 41-50 | 40(8.0) | | |
| 51-60 | 80(16.0) | Unemployed | 158(31.6) |
| >60 | 5(1.0) | Business | 70(14.0) |
| Ethnicity | | | |
| Saraiki | 215(43.0) | Govt. | 20(4.0) |
| Urdu | 108(21.6) | Laborer | 132(26.4) |
| Balochi | 95(19.0) | | |
| Monthly Income | | | |
| Sindhi | 3(0.6) | <5000 | 133(26.6) |
| Pathan | 29(5.8) | 5000-10000 | 168(33.6) |
| Punjabi | 50(10.0) | 10000-15000 | 106(21.2) |
| | | 15000-20000 | 93(18.6) |
The presence of a chronic disease like thalassemia places tremendous psychosocial and economic impact on patients and their families. The present study was designated to identify the psychosocial and economic impact of thalassemia major on patients’ families. Thalassemia patients required regular attention throughout their life. It is a lifelong illness and has devastating impact on the patients and their family life. The result of this study indicated that thalassemia major patient required blood twice a month to survive, which support the results of another study which were conducted in Karachi out of the total 221 patients 144(65%) required transfusion of blood twice a month. It is very difficult for the parents to arrange blood for their child twice in a month. The majority of the parents were illiterate and their monthly income was very low to bear the cost of the blood transfusion and medicines. Similar findings have been found in a previous study conducted by Sattari et al. Among the total respondents, 29(5.8%) have the knowledge that thalassemia is an inherited disease while majority 471(94.2%) respondents were not having the knowledge that thalassemia is an inherited disease. First cousin marriages were found, one of the major reasons in most of the thalassemia major families which is evident in the study conducted in Lahore showing the result (56%) of the couples were first cousins and (19.8%) were relatives. In our study majority of the parents reported that they faced restriction to participate in different family gathering while the Aziz et al. conducted study in Bahawalpur showed this rate to be 27 percent. The disease has affected parental financial state badly, the majority of the affected children's families were poor and unable to afford the costly treatment. Similar findings have been found in a previous study conducted by Sattari et al. In our study child disease effects the conjugal relationships, while the study in Iran showed this rate to be 14.1 percent. The majority of thalassemia major patients' parents knows regarding chelation therapy because Thalassemia Centre is providing the medicines with the help of Punjab Zakat & Ushr Department, Government of Punjab so the condition of thalassemia patients were much better. One of the most important limitations of the study is that all the patients were registered in the Thalassemia Centre of the Children’s Hospital & the Institute of Child Health Multan and may not be the representative of all thalassemia major patients of the Country. It is possible that those patients are registered in the other thalassemia centers may have different psycho-social and economic issues.

**CONCLUSION**

Vast majority of the parents was facing the socio-psychological and financial problems due to the chronic disease. It is the time to understand the density of the problem and create the thalassemia awareness program to prevent thalassemia disease from Pakistan.

**RECOMMENDATIONS**

- The study has recommended that measures to tackle and control the spread of thalassemia. The general awareness and the health education about thalassemia should be spread through print and electronic media.
- The thalassemia centers are advised to take measures for the maintenance of proper records and cooperation of the data collection. The Hospitals and the patient welfare societies must cooperate with the researchers, because the biggest problem for the researchers in Pakistan is data collection. This is not only the responsibility of Thalassemia Welfare Societies and Government Health Institutions to control the disease. But it is also the responsibility of every carrier thalassemia especially it is the duty of carrier mothers during their pregnancy to visit concerned doctors regularly.
- All the required medical equipment must be provided in every basic health units. Reasonable amount should be specified in the health budget by the government for the treatment of thalassemia and its prevention.
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REFERENCES