Original Article

Socio-Demographic Details and Psychological Aspects of Parents of Thalassemia Major Children

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ABSTRACT

Objective: To determine the socio-demographic details and psychological aspects of parents of Thalassemia Major Children.

Study Design: Cross sectional / observational study.

Place and Duration of Study: This study was conducted at the Thalassemia Center, Divisional Headquarters Teaching Hospital, Mirpur, AJK for a period of 09 months from February 2020 to October 2020.

Materials and Methods: Permission from Hospital Ethics Committee was taken before the study. An informed written consent was taken from parents. A questionnaire was designed that contained questions regarding demographic details as well as psychological aspects of children suffering from Thalassemia major. The data was analyzed by using SPSS version 23.

Results: 65 parents of children with Thalassemia Major were enrolled in this study. Out of 65 children, 34(52.3%) were male and 31(47.7%) were female children. The age of children was divided into groups, 23(35.4%) were between 1-5 years of age, 21(32.3%) in 6-10 years, 15(23.1%) in 11-15years and 06(9.20%) were more than 15 years of age. Education level of parents revealed, 8(12.3%) parents were totally illiterate, 47(72.3%) were under Matric pass, 08(12.30%) were Matric and 02(3.10%) parents were having Graduation level of education.

50(76.9%) parents reported consanguineous marriage while 15(23.10%) reported non-consanguineous marriage. Upon inquiry of parental screening, we found that 38 (58.5%) were not screened for carrier status and 27(41.50%) were screened.

37(56.90%) children were not attending any kind of school, 16(24.60%) were attending schools but with more leave days due to blood transfusions while 12(18.5%) were attending school normally. Majority of parents told that Hemoglobin should be kept between 7-8gm/dl before blood transfusion and 10gm/dl after blood transfusion. After recording demographic details, psychological aspects were explored by in depth interviews from the parents.

Conclusion: The existence of a chronic disease in a child leads to significant impact upon parents and that can predispose them to psychological disorders as well as financial problems.

Key Words: Thalassemia Major, Hemoglobin, Psychological, Pakistan

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INTRODUCTION

Thalassemia is one of the most commonly encountered hemoglobinopathy in the world[1,2]. Approximately 70,000 children are born annually with various forms of Thalassaemia[3].

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Except for a minority who are cured by Bone marrow transplantation, children and adolescents need regular blood transfusions along with iron chelation throughout their life[4,5]. They have comparatively short life span and poor quality of life due to chronic illness[6].

Due to its high prevalence worldwide, Thalassemia Major is considered to be a serious public health problem. Its presence spans the Mediterranean basin, African countries, the Middle East countries, the Indian Sub-continent, South-East Asia, Melanesia and the Pacific Islands, with the incidence from only 02% to as high as 25% in some parts of the world [7].

The mortality of Thalassemia is very high in poor and middle income countries reaching around 50,000 to 100,000 annually. Whereas, up to 07% of the world's population is a genetic carrier of this hemoglobin disorder[8]. Presently the estimated carrier rate is 5 to 7% in Pakistan. In future, the number of carriers is expected to rise up to 10 million. Due to limited local statistics and inadequate documentation, exact data indicating the

incidence and prevalence of the disease is not available. However, many studies indicate that the number of thalassemia major patients born each year is around 4000 to 9000[9]. The majority of Thalassemia children receive blood transfusions as the only treatment in Pakistan which creates a burden not only on health system but also on the affected families. These families are very much vulnerable to social, psychological and financial problems.

MATERIALS AND METHODS

This mixed method Study was carried out in the Thalassemia Centre, Divisional Headquarters Teaching Hospital, Mirpur, and Azad Kashmir. The study was carried out from 1st February 2020 to 30th October 2020. Permission from Hospital Ethics Committee was taken before the study. A total of 65 parents of children with Thalassemia Major were enrolled in this study after informed written consent. A non -probability convenient sampling technique was used. All Parents who brought their children for blood transfusion were added in the study. A self-designed Performa was used that had questions regarding demographic details and psychological aspects of children suffering from thalassemia major. The data was analyzed by using SPSS version 23.

RESULTS

A total of 65 parents of children with Thalassemia Major were enrolled in this study. Out of 65, 34(52.3%) were male and 31(47.7%) were female children. The age was divided into groups, 23(35.4%) were between 1-5 years of age, 21(32.3%) in 6-10 years, 15(23.1%) in 11-15yrs and 06(9.20%) were more than 15 yrs of age.

As far as education status was concerned, 8(12.3%) parents were totally illiterate, 47(72.3%) were under Matric pass, 08(12.30%) were Matric and 02(3.10%) parents were having Graduation level of education.

50(76.9%) parents reported consanguineous marriage while 15(23.10%) reported non-consanguineous marriage. Upon inquiry of parental screening, we found that 38 (58.5%) were not screened for carrier status and 27(41.50%) were screened. In this study, most of the children i-e 56.90% were not attending any kind of school, 24.60% were attending schools but with more leave days due to blood transfusions while 18.5% were attending school normally.

Knowledge about Hemoglobin levels before transfusion, majority of parents told that it should be kept between 7-8gm/dl before blood transfusion and 10gm/dl after blood transfusion.

Table No.1: Questions and Answers thereto

Sr.#	Question Explored	Answers given by Parents:			P-Value
1	Do you have disturbed feeling?	Yes (n=59 90.8%)	No (n=6 9.20%)	Missing (nill)	0.002
2	Are you able to Concentrate upon work?	Not at all (n=12 18.50%)	Moderately effected (n=32 49.2%)	Normal work (n=21 32.3%)	0.061
3	Effect of child's disease on your eating habits?	No effect (n=25 38.50%)	Moderately (n=35 53.80%)	Excessively (n=5 7.70%)	0.003
4	Effected sleep pattern or not?	Not at all (n=23 35.4%)	Moderately (n=33 50.8%)	Excessively (n=9 13.8%)	0.120
5	Effect of disease on economic status?	Not at all (n=4 6.20%)	Moderately (n=42 64.60%)	Excessively (n=19 27.70%)	0.004
6	Attend social Gatherings or not?	Normally (n=20 30.80%)	Moderately restricted (n=39 60.0%)	Excessively limited (n=5 7.70%)	0.137
7	Effect on Relation with spouse due to disease?	Yes, badly effected (n=14 21.50%)	No effect (n=50 76.90%)	Don't want to answer (n=01 1.50%)	0.004
8	Do you take any Drug to relieve tension?	Yes (n=08 12.30%)	No (n=57 87.69%)	Missing (nill)	0.191
9	Would you go for termination if antenatal diagnosed?	Yes (n=35 53.80%)	No (n=30 46.15%)	Don't want to answer (n=1, 1.50%)	0.078
10	Effect Thalassemia on family size?	Yes reduced size (n=18 27.70%)	No (n=47 72.30%)	Missing (Nill)	0.065
11	Would you do marriage of children in family?	No (n=53 81.50%)	Yes (n=12 18.50%)	Missing (Nill)	0.043
12	Any knowledge of thalassemia before your own child?	No (n=54 83.10%)	Yes (n=11 16.90%)	Missing (Nill)	0.152
13	Any Knowledge about prenatal screening?	No (n=38 58.50%)	Yes (n=27 41.50%)	Missing (Nill)	0.062
14	Have you opted prenatal diagnosis?	No (n=51 78.50%)	Yes (n=14 21.50%)	Missing (Nill)	0.342
15	What are the management options?	Transfusion (n=19 29.20%)	transfusion and chelation (n=38 58.50%)	BMT (n=8 12.30)	0.143

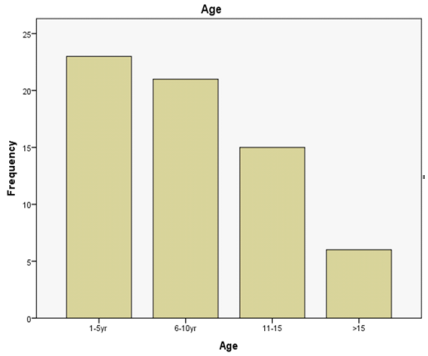

Figure No.1: Age and frequency

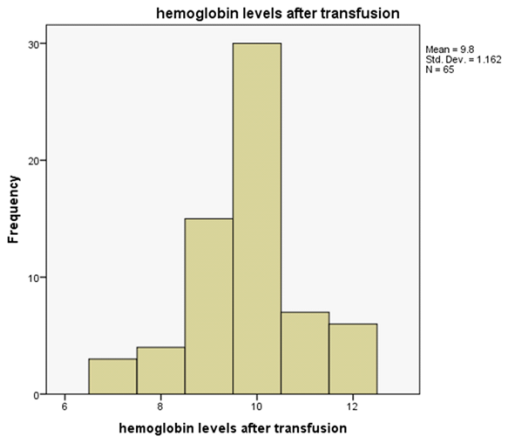

Figure No.2: Hemoglobin levels after transfusion

In-depth exploration of psychological aspects of parents revealed that 59(90.80%) had disturbed feeling with an element of depression and deprivation and 06(9.2%) had normal feeling towards their children. P-value was found to be significant (<0.005) for disturbed feelings, parental eating habits, poor effect on economical status and disturbed relationship with the spouse.

DISCUSSION

A total of 65 parents were enrolled in this study. The age was divided into groups, 35.4% were between 1-5 years of age, 32.3% in 6-10 years, 23.1% in 11-15years and 9.20% were more than15 years of age. Our study is comparable with study done by Rifaya et al. Who took 50 parents as sample[10].

The rate of consanguineous marriage in our study was very high i-e 76.90% while 23.10% reported non-consanguineous marriage. This is similar to another local study done in Bahawalpur, where 80% were consanguineous marriages[11]. This is in contrast to international studies where Khamoushi et al reported 57.8 % of the parents with consanguineous marriage[12].

Due to conventional religious and cultural traditions, premarital screening and prenatal diagnosis are not common among the families in Pakistan. Upon inquiry of parental screening, we found that 58.5% were not screened for carrier status and 41.50% were screened.

In this study, most of the children i-e 56.90% were not attending any kind of school, 24.60% were attending schools but with more leave days due to blood transfusions while 18.5% were attending school normally. Similarly, in a study done in Qatar, it was seen that Thalassemia patients missed schools more than healthy children due to not feeling well as well as transfusions. They were more forgetful and their school functionality and keeping up with school was remarkably less. Furthermore, their power of attention was relatively lower than their healthy peers as well[13].

Regarding Hemoglobin levels before transfusion, majority of parents told that it should be kept between 7-8gm/dl before blood transfusion and 10gm/dl after blood transfusion.

In-depth exploration of psychological aspects of parents revealed that 59(90.80%) had disturbed feeling with an element of depression and deprivation and 06(9.2%) had normal feeling towards their children. This is comparable with a study done in Iran where patients with thalassemia were found to have a low Quality of life than their age fellows (P = 0.001) and depression was significantly higher in this group (P = 0.015)[13].

12(18.50%) parents reported that they are not at all able to concentrate upon their daily work and jobs due to their child's illness, 32(49.20%) reported moderate difficulty in concentration while 21(32.30%) had normal concentration and ability to perform their daily duties. This is very high as compared with study done by Aziz et al where only 08% reported that the disease did not affect their daily jobs whereas 92% had an effect upon their work[8].

25(38.50%) parents reported normal eating habits, 35(53.80%) had moderate effect on eating habits while 05(7.70%) reported severe effect on their eating habits including loss of appetite, acid peptic disease and epigatric pain.

23(35.40%) parents had normal sleep pattern with some having severe fatigue during travelling for transfusions followed by deep sleep, 33(50.80%) had mild to moderate sleep loss and 09(13.80%) had severe insomnia due to depression and anxiety about their child.04(6.20%) had no impact of their child's disease on economic status, 42(64.60%) had moderate impact while 19(27.70%) parents had major impact in terms of inability to meet travelling expenses as well as cost of chelation therapy. Zaheer et al also demonstrated that cost of treatment, unavailability of blood, hospitalization and traveling to the health centers is adding more to the anxiety of the parents. In his study, most of the parents confessed crying about the situation and having disturbed sleeping patterns[14].

20(30.80%) parents were not having any problem in attending social gatherings, 39(60.00%) had moderately restricted social life while 05(7.70%) parents had severely restricted social life due to very frequent transfusions, stigma of disease, depression and financial

problems. Aziz et al. conducted a study in Bahawalpur showed this rate to be 27% [8].

50(76.90%) had good relation with their spouse along with supportive attitude while 14(21.9%) were having problems in their relation with spouse in the form of financial support, bringing to thalassemia center for transfusion, abusive language, blame for disease and even divorce. 01(1.5%) refused to answer this question. Another study reported that 23 % had family conflicts with their spouse[8].

The appropriate strategy to reduce Thalassemia is prevention. There are different ways to decrease the incidence of Thalassemia including population screening, parental education, prenatal diagnosis and genetic counseling. Turkey, Cyprus and Iran have implemented various strategies of Thalassemia prevention[15].

27.70% parents reported reduced family size due to fear of another Thalassemic child while 72.3% had no impact on family size. Upon inquiry about future marriage of effected children in family revealed 81.50% parents not willing for consanguineous marriage while 18.50% were willing for family marriage. An Iranian parent describes this phenomenon as "Life begins with joy and a lot of aspirations but it changes its face soon after the disease was diagnosed at birth of first child. The Thalassemic child is born again among other healthy children and the happiness disappears. Our worries for the future of our Thalassemic children deprive us from life pleasure and the life color changes into gray, but because there are healthy children, it is not yet black" [16].

Inquiry about prior disease knowledge before their own Thalassemic child revealed that 83.10% parents had no idea about it while 16.90% had some idea from either relatives or community. 78.50% parents never opted for prenatal screening in further pregnancies either due to lack of knowledge or finances and 21.5% opted prenatal screening in further pregnancies. 58.50% were not knowing about availability of prenatal screening while 41.50% knew about prenatal screening. 55.4% parents didn't go for termination after prenatal diagnosis while 44.6% opted TOP. Ishfaq et al. Showed that the majority of the parents were illiterate and their monthly income was very low 11 to bear the cost of the blood transfusion and medicines. Among the total respondents, 5.8% had the knowledge that Thalassemia is inherited disease while majority 94.2% respondents were not having the knowledge that thalassemia is an inherited disease[15].

Regarding disease awareness, 29.2% knew about blood transfusions, 58.50% knew about chelation therapy along with blood transfusions while 12.30% knew about bone marrow transplant as well. Parental awareness in other studies regarding the Thalassemia management was also inadequate and patients continue to suffer a slow and painful course ultimately leading to death[17].

CONCLUSION

Thalassemia being a chronic disease, significantly affects the families in all aspects. It is a preventable illness so parents should be supported both psychologically as well as financially.

Recommendations: Thalassemia awareness should be increased through health education of society. Counseling experts should be appointed at Thalassemia centers in Pakistan. Prenatal diagnosis should be provided to all effected couples in subsequent pregnancies.

Author's Contribution:

Concept & Design of Study:	Saba Haider Tarar
Drafting:	Toqeer Ahmed, Abubakr Ali Saad
Data Analysis:	Waseem Ahmed Khan
Revisiting Critically:	Iftikhar Ahmed
Final Approval of version:	Saba Haider Tarar

Conflict of Interest: The study has no conflict of interest to declare by any author.

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