ORIGINAL RESEARCH PAPER

Social Science

PREVALENCE AND BURDEN OF PSYCHOLOGICAL PROBLEMS AMONG THE PARENTS OF THALASSAEMIA MAJOR CHILDREN

KEY WORDS: Thalassaemia, Disease, Psychological Problems, Thalassaemia Major

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ABSTRACT

Background: Thalassaemia is a hereditary disease that results in reduced production of haemoglobin. Statistics reveal that every year in India thalassaemia major affects over 1, 00,000 people and over 8,000 reported with thalassaemia and there are, however, many more unreported cases as well. Control of thalassaemia in India is a major problem because of ignorance about the chronic disease, social, cultural and religious taboos, customary practices and family influences. **Objectives:** 1. To study various psychological problems faced by the parents of the children suffering from thalassaemia major. 2. To study association between some of the selected dependent and independent variables **Methods:** The present descriptive study was conducted in selected Branches of Indian Red Cross Society of Ahmedabad and Vadodara of Gujarat State. The study was conducted during 2017-2020. Disproportionate Stratified Random Sampling method was used for data collection. Total 306 respondents of thalassaemia major children constituted the sample size. Data was collected in a predesigned structured proforma. Data was entered and analyzed by using SPSS. Test of significance (Chi square test) was used where ever necessary. A probability value of <0.05 was taken as statistically significant. **Findings:** Majority of the respondents i.e.75.2% strongly agree about feeling guilty where as 78.8 % have "why me syndrome" because of having thalassaemia major children.

INTRODUCTION

Thalassaemia is a genetic blood disease. People with Thalassaemia disease are not able to make enough haemoglobin, which causes severe anemia. There are two primary types of thalassaemia disease: Alpha thalassaemia disease and Beta thalassaemia disease. Beta thalassaemia major (also called Cooley's Anemia) is a serious illness.

Worldwide, approximately 15 million people are estimated to suffer from thalassaemia disease. In India the burden of haemoglobinopathies is very high with nearly 12,000 infants being born each year with a severe disorder. These numbers imply that in every hour 1 child is born who will suffer with this genetic disorder. The carrier rate for β - thalassaemia varies from 1-17 % in India with an average of 3.2 %. This means that on an average 1 in every 25 Indians is a carrier of thalassaemia.[2]

The most common treatment thalassaemia major is red blood cell transfusions. These transfusions are essential to provide the patient with a temporary supply of healthy red blood cells with normal haemoglobin capable of carrying the oxygen that the patient's body demands.

The best way to reduce the burden of thalassaemia is prevention. However, the quality of life of children with thalassaemia should be improved. There are various strategies to prevent thalassaemia, which include parental awareness, population screening, genetic counselling, and prenatal diagnosis. Awareness generation and educating parents and youth proved to be cost-effective in the prevention of the chronic disease and improvement in quality of life of patients with thalassaemia.

OBJECTIVES:

1. To study various psychological problems faced by the parents of the children suffering from thalassaemia major.
2. To study association between demographic variable namely age, gender, education of the respondents and respondents' spouse, occupation of the respondents and respondents' spouse, income, period of care and type of family and psychological problems.

MATERIALS AND METHODS:

The present descriptive study was conducted in selected Indian Red Cross Society of Ahmedabad and Vadodara Branches of Gujarat State. The study was conducted during 2017-2020. Disproportionate Stratified Random Sampling method was used for data collection. Total 306 respondents of thalassaemia major children constituted the sample size. Data was collected in a predesigned structured proforma. Data was entered and analyzed by using SPSS. Test of significance (Chi square test) was used where ever necessary. A probability value of <0.05 was taken as statistically significant.

REVIEW OF LITERATURE:

Ishfaq, K. et al. (2016) conducted a study on 'Psycho-social and economic impact of thalassaemia major on patients' families' with the objective to identify the psycho-social and economic impact of thalassaemia major on patients' families. A cross sectional study was conducted to identify the psycho-social and economic impact of thalassaemia major on patients' families. The present study was conducted and included 500 registered thalassaemia major patients' parents from the Thalassaemia Centre, The Children's Hospital & the Institute of Child Health Multan. The researcher used the structured interview as a tool for data collection with the help of convenient sampling. The study revealed that total 221 patients 65 % required transfusion of blood twice a month. It was 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. Majority of the parents reported that they faced restriction to participate in different family gathering. The study concluded that a substantial number of parents have psycho-social and economic problems due to the thalassaemia major disease of their child. 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. Parents hesitated while talking about the disease with others.

Sultana, R. et al. (2016) carried out a study on 'Psycho-social Problems in parents of thalassaemia

children' from Thalassaemia Centre Sir Ganga Ram Hospital, Lahore. The Cross-sectional study was conducted with an aim to determine the psychosocial impact of disease on parents of children affected with beta thalassaemia major. A structured proforma comprised of 23 questions including Patient Health Questionnaire 9 (PHQ - 9) was used. The study revealed that hundred and twenty-seven couples have one thalassaemia child and 73 had two or more thalassaemia children. Study also revealed that thalassaemia has affected the economic condition of parents in 174, family life in 133, conflicts with spouse in 19, downgrading by relatives in 47 and 6 were on medication to relieve tension. The present study also showed that depression was significantly higher in female than males (p=0.00). However, there is no significant association of age and literacy status with depression (p=0.22). Also, there is no significant association (p=0.61) between education status and depression. There is significant association found between income and depression among the respondents (p=0.01). The study concluded that parents of thalassaemia children face number of psycho-social problems requiring continuous counselling and psychological support.

Zaheer, Z. et al. (2015) stated in their study entitled 'Psychological burden in b-thalassaemia affected families' that 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 various factors on social life differs for male and female patients. The objective of the study was to assess the psychological burden on families affected by thalassaemia may face, controlling for cultural and social setup. A cross-sectional survey was done with the help of structured interviews and questionnaires. The survey was carried out in different health centers of Peshawar that specialize in providing medical facilities to patients suffering from blood diseases. The results revealed that the parents of a thalassaemic patient face problems with social interaction. There was high significant association between social life and locality of the respondents (p= 0.015). Social life of the parents was having non-significant association with type of the family (p=0.075). They were 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. 96% of the parents were anxious for their children. Moreover, the results showed that thalassaemia is not the only concern for the parents but other associated disease with thalassaemia such as heart diseases also cause them anxiety. The fear that the child may not survive for long and was in pain causes them stress.

RESULTS AND DISCUSSION

From the table 1, it can be seen that majority of the respondents i.e. 75.2% strongly agree about feeling guilty where as 78.8 % have "why me syndrome" because of having thalassaemia major child or children. It is also found that most of the respondents say 46.1% strongly agree that they feel depressed and anxious, 44.1% agree that they are unable to give time to themselves where 60.5% agree that they feel their life is unsuccessful and messed-up and almost half of the respondents say 50% strongly agree that they feel their physical and mental health is affected due to their maximum involvement in caring of their child or children. The finding of the study carried out by Siddqui, M. (2015) support the finding of the present study. He found that majority of the respondents had feeling of their life become unsuccessful and messed-up. Even they have faced mental stress because of child's disease. In addition, majority of the respondents had feeling that their life is not successful and under mental stress to a great extent. (Ishfaq, k. et al. 2013)

Table 1 Showing Distribution of Psychological Problems of the Respondents having Thalassaemia Major Children. (N=306)

Psychological Problems of the Respondents	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total
Feeling of guilty	230 (75.2)*	64 (20.9)	7 (2.3)	5 (1.6)	0	306 (100)
Feeling depressed and anxious	141 (46.1)	134 (43.8)	14 (4.6)	17 (5.6)	0	306 (100)
Feeling "why me syndrome"	241 (78.8)	47 (15.4)	10 (3.3)	8 (2.6)	0	306 (100)
Unable to give time to themselves	135 (44.1)	138 (45.1)	23 (7.5)	10 (3.3)	0	306 (100)
Feeling of unsuccessful and messed-up life	49 (16)	185 (60.5)	36 (11.8)	36 (11.8)	0	306 (100)
Feeling physical and mental health is affected	153 (50)	115 (37.6)	15 (4.9)	23 (7.5)	0	306 (100)

* figure in parentheses indicates percentage **(Source: Field Survey)**

From the table 2, it is found that there is high significant association between psychological problems of the respondents and gender (.000) and occupation of the respondents (.000). The results of the study carried out by Sultana, R. et al. (2016) support the present study. Psychological problems were significantly higher in female respondents than male (p=0.00). There is found significant association between psychological problems of the respondents and period of care (.005) There is found non-significant association between psychological problems and age (.067), education of the respondents (.416) education of the respondents' spouse (.414), type of family (.124) and psychological problems. The finding of the study conducted by Aziz, A. et al. (2015) does not support with the findings of present study which shows that there is non-significant association between occupation and psychological problems of the respondents. (p=0.59214722).

Table 2 showing Cross Tabulation between Socio-Demographic variable and psychological problems of the respondents. (N=306)

Socio-Demographic Variable	Psychological problems			Total	P value
	High	Moderate	Low		
Age Group					
21 to 25 Years	15	2	0	17	**.067**

26 to 30 Years	46	2	0	48	
31-35 Years	121	10	2	133	
36 to 40 Years	59	8	2	69	
Above 40 Years	28	9	2	39	
Total	269	31	6	306	
Gender					
Male	96	28	5	129	**.000**
Female	173	3	1	177	
Total	269	31	6	306	
Education of the Respondent					
Illiterate	9	0	0	9	**.416**
Primary	18	1	1	20	
Secondary	42	2	0	44	
Higher Secondary	102	10	1	113	
Graduation	75	15	2	92	
Post Graduation	23	3	2	28	
Total	269	31	6	306	
Education of the Respondents' Spouse					
Illiterate	6	2	0	8	**.414**
Primary	10	0	0	10	
Secondary	39	1	0	40	
Higher Secondary	79	12	3	94	
Graduation	63	9	3	75	
Post Graduation	45	5	0	50	
Not Applicable	27	2	0	29	
Total	269	31	6	306	
Occupation of the Respondent					
Business	5	1	1	7	**.000**
Govt. Service	32	3	1	36	
Private Service	58	10	2	70	
Labour Work	102	5	0	107	
Agriculture	26	11	2	39	
Unemployed	46	1	0	47	
Total	269	31	6	306	
Period of Care					
Less than 1 Year	7	1	0	8	**.005**
1-5 Years	144	8	2	154	
6-10 Years	77	13	1	91	
More than 10 Years	41	9	3	53	
Total	269	31	6	306	
Type of family					
Nuclear	82	3	2	87	**.124**
Joint	181	28	4	213	
Extended	6	0	0	6	
Total	269	31	6	306	

CONCLUSION:

Thalassaemia has multifaceted psychological implications on parents of thalassaemia children. Thus, the present study concluded that vast majority of the respondents were facing the psychological problems due to the chronic disease. It is the time to understand the density of the problem hence there is a need for creating awareness among families with thalassaemia and the general public in order to reduce the burden of thalassaemia from the community so that children with thalassaemia may have a better life.

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