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PSYCHO-SOCIAL PROBLEMS FACED BY THE PARENTS OF THALASSEMIA AFFECTED CHILDREN

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ABSTRACT

Thalassaemia is a genetic disorder that results in reduced production of haemoglobin. Statistics reveal that in India thalassaemia major affects over 1, 00,000 people and over 8,000 reported thalassaemia births take place each year. There are, however, many more unreported cases as well. Control of thalassaemia in India is a major problem due to ignorance about the disease, social, cultural and religious taboos and family influences. This study was conducted to determine psycho-social problems faced by the parents of thalassaemia affected children. Stratified random sampling with structured interview schedule has been used for the study with purpose to collect the responses. A descriptive research carried out at Anand and Baroda branches of Indian Red Cross Society and Shri Krishna hospital Karamsad in Gujarat, India in the year 2011-12. The study revealed that 47(78.33 %) feels that thalassemia occurs after 5 year which shows awareness among parents were inadequate. In this study, it can be analysed that 25% respondents face psychological problem of depression, 51.67% anxiety, 18.33% suicidal tendency, 1.67% respondents face Loneliness and 3.33% respondents face psychological problem like Inferiority complex.

KEYWORDS : Thalassaemia, Knowledge, Disorder, Depression, Inferiority

INTRODUCTION:

Thalassaemia is a genetic blood disorder. People with Thalassaemia disease are not able to make enough haemoglobin, which causes severe anemia. Haemoglobin is found in red blood cells and carries oxygen to all parts of the body. If there is not enough haemoglobin in the red blood cells, oxygen cannot get to all parts of the body. Organs then become starved for oxygen and are unable to function properly.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. Symptoms appear in the first two years of life and include paleness of the skin, poor appetite, irritability, and failure to grow. Proper treatment includes routine blood transfusions and other therapies.[1] Worldwide, approximately 15 million people are estimated to suffer from thalassaemic disorders. About 240 million carriers of β-thalassaemia worldwide, i.e. 1.5% of world population, and in India alone, the number is approximately 30 million with 505 in South East Asia. 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 for all major forms of thalassaemia is red blood cell transfusions. These transfusions are very much important 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. Today, most of the patients with thalassaemia major receive red blood cell transfusions every two to three weeks. Chelation therapy is another common treatment as by this excessive iron is removed from the body as the patient undergoes the difficult and painful infusion of a drug named Desferal. However, bone marrow transplantation or gene therapy may totally cure a case of thalassaemia major; as this therapy is very expensive rare one can afford it. But for all practical purposes transfusion of red cell concentrate in the only path to sustain the life of a thalassaemia patient at present.[3]

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 different 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 disease and improvement in quality of life of patients with thalassaemia.[4,5]

OBJECTIVES:

1. To assess the family awareness pertaining to thalassaemia.
2. To study the psycho-social impacts on parents of thalassaemia affected children.

METHODOLOGY:

The study was conducted from Anand and Baroda branches of Indian Red Cross Society along with Shri Krishna Hospital, Karamsad, and Gujarat in the year 2011-12. The respondents of this study were sixty parents of thalassaemia affected children. The data was collected using a structured interview schedule and prepared by researcher. Researcher was applied stratified random sampling method for the data collection and type of research was descriptive research. Collected data analysed using descriptive statistics and presented in frequency and percentage.

DISCUSSION:

A total of sixty parents were consented to participate in the study. The distribution of beta thalassemia is not uniform in the Indian subcontinent. Though certain communities are identified to have high prevalence, it has been detected in almost every Indian population. The prevalence of beta thalassemia trait varies from 1-17% in different populations of India.[6,7]

Regarding the personal information of the study population, from the **Table 1** it was seen that out of total 60 parents, 35 (58.33%) were males; while 25 (41.47 %) were females. In the present study 15 (25%) respondents are belong to age group of 36 to 40 year & 40 years & above. that shows upper middle aged group. Majority of 35(58.33%) respondents are belongs to Muslim religion which indicated that the vulnerability of some religion towards developing this genetic disorder. In the study, 25(41.67%) respondents are graduates which shows that parents are educated enough to understand the situation.

Table 1 showing demographic information of the respondents.

Demographic Information	Frequency	Percentage
Age		
20 to 25	11	18.33 %
26 to 30	10	16.67 %
31 to 35	09	15 %
36 to 40	15	25 %
40 years & above	15	25 %
Gender		
Male	35	58.33%
Female	25	41.67%

Religion		
Hindu	15	25%
Muslim	35	58.33%
Christian	10	16.67%
Education		
Primary	05	8.33%
Secondary	10	16.67%
Higher secondary	08	13.33%
Graduate	25	41.67%
Post-Graduate	12	20%
Type of Family		
Joint	25	41.67%
Nuclear	35	58.33%

Table 2 revealed the basic information pertaining to thalassaemia among the respondents. In the present study, majority of 47(78.33 %) feels that thalassemia occurs after 5 year which shows awareness among parents were inadequate. Regarding causes of disease, 15% respondents believed that thalassemia happens to be a hereditary endowment ,38.33% respondents believed that thalassemia is due to viral disease, where as 46.67%% respondents are believed that thalassemia is bacterial disorder which is again a myth & not a reality. In the study, 55(45%) respondents believed that occurrence of thalassemia is in the hands of God which is again showing the agony that parents are not fully aware about the causes of thalassaemia. As far respondent's views for treatment place is concerned 63.33% respondents said that they have will go to hospital first, 35% respondents said that they will go to temple, 1.67% respondents said that they will go to jyotish which again shows religious stereotypes.

Table 2 showing respondent's primary information regarding thalassaemia

Primary Information regarding thalassaemia	Frequency	Percentage
Causative age of thalassaemia		
Inborn	04	6.67%
After 5 year	47	78.33%
After 10 year	09	15%
Factors responsible for thalassaemia		
Hereditary	9	15%
Viral disease	23	38.33%
Bacterial disease	28	46.67%
Belief regarding thalassemia that it is in god' hand		
Yes	33	55%
No	55	45%
Respondent's views regarding places of treatment		
Hospital	38	63.33%
Temple	21	35%
Jyotish	01	1.67%

Table 3 provided information regarding psycho-social effects of parents having thalassaemic children. In the present study, 33.33% respondents get support from family while 66.67% respondent's family does not get support from family. 40 (66.67) parents didn't get family support as well as not attended any family function which shows voluntary social withdrawn. About 35 (58.33%) faced problem of domestic violence. Majority of that respondents 49(56.67%) have major failure in their life because of their child/children were suffering from the disease. In this study, it can be analysed that 25% respondents face psychological problem of depression, 51.67% anxiety, 18.33% suicidal tendency, 1.67% respondents face Loneliness and 3.33% respondents face psychological problem like Inferiority complex.

Table 3 showing psycho-social impacts on parents of thalassaemia affected children

Psycho-social impacts	Frequency	Percentage
Family Support		
Yes	20	33.33%
No	40	66.67%
Social function		
Yes	20	33.33%
No	40	66.67%
Psychological problems		
Depression	15	25%
Anxiety	31	51.67%
Suicidal tendency	11	18.33%
Loneliness	1	1.67%
Inferiority	2	3.33%

CONCLUSION:

It was seen from our study that general public don't have adequate knowledge on thalassemia. Health education on the knowledge and prevention of thalassemia needs to be implemented on a much larger scale. Awareness program with community participation will be effective as people witness the seriousness of the disease in their day-to-day life. Social work intervention is very much helpful and necessary in this phase as thalassaemia is life threatening situation and deals with psycho-social as well as economic aspect of someone's life. There is a need for creating awareness among families with thalassaemia and the general public with the help of mass media, booklets, lectures, video, etc., so that the burden of thalassaemia in the community can be reduced and children with thalassaemia may have a better life.

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