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STRESS LEVEL AMONG CAREGIVERS OF THALASSEMIA PATIENTS

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ABSTRACT

Introduction: Children with Thalassemia have to regularly attend hospital for blood transfusion and chelation therapy. Parents suffer from psychosocial burden because of expenses, stress and fear of death.

Material and Methods: It is a cross sectional interview based study. Thirty five Care giving parents were interviewed in the day care centre of anemia in Choithram Hospital Indore. Two proformas were used. One for general information and the other one was the Zarit Burden Interview scale.

Results: The parents were under stress (60.6%).There was no difference statistically between school and college educated caregivers of psychosocial burden. Knowledge regarding prevention of Thalassemia by pre marriage genetic counseling and testing was very poor among parents.

Conclusion: The parents of Thalassemic children need to receive health education about the disease and required treatment. They need psychosocial counseling and support.

Key words: Thalassemic children, Caregivers, Psychosocial burden, knowledge

INTRODUCTION

Thalassemia refers to a group of genetic disorders, characterized by insufficient production of hemoglobin(blood)[1].Three percent of the world's population carries genes for beta Thalassemia.[2] Mediterranean people with both parents heterozygous for beta thalassemia are at risk of producing homozygous children.[3] Around 4% of the existing population in India carries the Thalassemic genes.[1]

Although optional medical management has reduced the difficulties faced by Thalassemic children and their families, still the psychosocial impact on the development of the sick children and family is a continuous process throughout life. Children with Thalassemia have to regularly attend hospital for blood transfusion and chelation therapy. Parents suffer from psychosocial burden because of expenses, stress and fear of death.[4] It is possible that uneducated, poor and socially maladjusted parents are more affected in comparison to those who are educated, economically sound and socially well adjusted. The psychosocial burden can affect the quality of life of the families. Less work has been done regarding the stress level of parents who are giving care and love to these chronically ill children.

A study, therefore, was planned aiming to assess the psychosocial burden and the basic knowledge of the illness among caregiver parents. It would enable health care providers to assess family caregivers at risk and provide interventions to improve their quality of life.[5]

MATERIAL AND METHODS

Total 162 patients are registered in Indore district. The children with their parents are registered in an association of Thalassemic pateints.

There is a day care centre for Thalassemic patients in Choithram Hospital. Forty seven patients are registered in this hospital. The patients are regularly coming to this centre with their parent caregiver for blood transfusion and other disease management.

This is a cross sectional interview based study. The interview was taken by distributing two proformas to the parents of children suffering from Thalassemia. Proforma I contains general information about them and the illness. Proforma II is a scale to measure the psychosocial burden during illness. It is a 'Zarit Burden Interview' provided by Department of Psychology, NIMHANS, India.[5] There are 22 questions in the scale with a minimum score of zero and maximum score of four in each question.

The total score is out of 88. The interpretation of score:

0 - 21	Little or no burden
21- 40	Mild to moderate burden
41- 60	moderate to severe burden
61- 88	Severe burden

The instructions were given in the beginning about filling the proforma. Parents were given sufficient time to fill the proforma. Out of the total registered cases, only 35 caregivers filled the proforma. Genetic counseling was done at the end of the interview. The statistical analysis has been done manually with the help of calculator.

RESULTS

After the analysis it was observed that most of the caregivers want that their child should be cured and live a healthy long life.

Overall 60.6% parents were burdened. The mothers and fathers were burdened equally statistically. As per percentage, moderate to severe burdened fathers were 11.43 as compared to mothers 8.57.

Around 63% of the parents were graduate and postgraduate. Mild to severe burden was found to be more among school educated (28.57%). Little to no burden was seen among 31.42% college educated parents as compared to school educated 8.57%. The level of burden showed no difference with level of education statistically.

Table 1: Level of burden amongst the parents

Level of burden	Mother (n=15) (%)	Father (n=20) (%)	Total (n=35) (%)	Chisquare (p value)
Little or no burden	4(11.43)	10(28.57)	14(40)	2.49 (0.2875)
Mild to moderate	8(22.86)	5(14.28)	13(37.14)	
Moderate to severe	3(8.57)	4(11.43)	7(20.6)	
Severe	0	1(2.86)	1(2.86)	

Table 2: Level of burden according to education of parents

Level of burden	School education (n=13) (%)	College education(n=22) (%)	Total (n=35)(%)	Chi-square
Little or no burden	3(8.57)	11(31.42)	14(40)	3.679
Mild to moderate	5(14.28)	8(22.86)	13(37.14)	p=0.2231
Moderate to severe	4(11.43)	3(8.57)	7(20)	
Severe	1(2.86)	0	1(2.86)	

Table 3: Knowledge of parents about the illness

Knowledge	Mother(N=15) (%)	Father (N=20) (%)	Total (%)	P value
Naming Thalassemia	13 (37.14)	15 (42.86)	28 (80)	0.97
Genetic disease	10(28.57)	14(40)	24(68.57)	0.0439
Treatment by bone marrow transplant	5(14.28)	11(31.43)	16(45.7)	1.6185
Treatment by blood transfusion and chelating agents	11(31.43)	16(45.7)	27(77.14)	0.2127
Preventable	5(14.28)	7(20)	12(34.28)	0.1239
Premarriage genetic counseling and testing	5(14.28)	6(17.14)	11(31.43)	0.2452

The knowledge regarding illness and its treatment was well among the parents (80, 68.57 and 77.14%). There was poor knowledge among parents about the premarriage counseling as a method of prevention (31.43%). They were unaware that Thalassemia is a preventable disease (34.28%).Very less no. of parents(45.7%) were aware that bone marrow transplantation is a treatment option, which if done timely would produce better results. The difference in knowledge about the disease among mothers and fathers was found to be insignificant.

Table 4: Knowledge of parents according to their education

Knowledge	School (N= 13) (%)	College Education (N= 22) (%)	Total (%)	P value
Naming Thalassemia	10(28.57)	18(51.43)	28(80)	0.2656
Genetic disease	8(22.86)	16(45.71)	24(68.57)	0.4742
Treatment by bone marrow transplantation	5(14.28)	11(31.43)	24(68.57)	0.3168
Treatment by blood transfusion & chelating agents	10(28.57)	17(48.57)	27(77.14)	0.1900
Preventable	5(14.28)	7(20)	12(34.28)	0.1615
Premarriage genetic counseling and testing	4(11.43)	7(20)	11(31.43)	0.0955

Those who were college educated had better knowledge about the name, genetic origin and treatment of disease (80%, 68.57%, 68.57% and 77.14%). There was minimal knowledge about preventability and premarriage counseling (34.28% and 31.43%)

DISCUSSION

The chronicity and complications of Thalassemia affect the quality of life of victims and parents and cause physical, psychological and economic problems. As there is no definitive cure for this disease, the majority exclusively depend on blood transfusions as a treatment option **that creates a burden not only on health** system but also on affected families. This makes such families vulnerable to social and psychological problems.[6]

In this study parents were assessed by Zarit burden scale. 60.6% were moderate to severely burdened due to illness of their children. This burden was found to be29% in the form of depression, whereas 16% had sleep disturbance in a study conducted in Pakistan.[7] Parents (caregivers) of Thalassemic children reported being more stressed, strained, embarrassed and afraid of their child's future as per Pruthi et all.[1]

There was adaptation of parents towards illness in a study conducted across a number of cultures where disease is prevalent.[8] The quality of life was affected adversely among 50% of caregivers of Thalassemia pateints at Banglore.[9] All the parents of Thalassemia children were found to have severe parental stress assessed by Parental Stress Scale (PSS) in Rawalpindi.[10]

In the present study, 73.33% of mothers were burdened by illness of their children. Similarly data were expressed by a study in which 76% of women caregivers had poor quality of life.[9] With the help of General Health Questionnaire Shazia Ali et all found that mothers have more distress than fathers.[10] Quality of life of caregiving mothers was poor as assessed by World Health Organization Quality of life questionnaire (WHOQOL-BREF).[11] The mothers of children with Thalassemia were found to have higher depression score as assessed by Beck Depression Inventory at Iran.[12]

The stressors experienced by parents of children who are chronically ill usually are multiple and ongoing. Although these stressors vary over time, they can be categorized as those that parents experience: a. At the time of diagnosis, b. During developmental transitions, c. That are related to the ongoing health care needs of their child, d. And as their child experiences illness exacerbations and hospitalizations.[13]

Most of the parents in this study were college educated and no burden was found among 31% parents. Similarly 59% of the fathers in the study who had less than primary school education had more caregiver's concern.[9]

As found by T. Siantis, fathers' low education level was the predictor of poor family adjustment.[8] It was found in a study that higher educated mothers had overprotective attitudes towards their ill children.[14]

There was poor knowledge about the genetic origin, bone marrow transplant as treatment and preventability of the disease among mothers in this study. Similarly lack of knowledge about Thalassemia among mothers was found in Thailand.[15]

Fourteen percent of the mothers knew about bone marrow transplantation and only 29% were aware of blood transfusion and chelating agents as being essential for the treatment of their children in this study. A study in Taiwan explains that the average of mothers' knowledge was 16.44. However practical knowledge should improve patient adherence to treatment.[16]

In this study, higher education was seen among 63% parents. That the disease is of genetic origin was known to 68.6%. Awareness about treatment by blood transfusion and chelating agents was among 77.14%. Thirty one percent were aware of premarriage counseling and testing. In a study with 2.5% higher educated parents, the genetic origin was known to 15%. Fifty five percent parents were aware that child should receive chelating agent and 12 percent were aware of consanguinity as risk factor.[17]

There is need to take care of anxieties and worries of Thalassemic adolescents and parents to prevent the development of further emotional and adjustment problems.[18]

CONCLUSION

The parents of Thalassemics are burdened and under stress because of the chronic nature of the illness. Timely decisions, however, can, over the long term, reduce this stress.

RECOMMENDATION

Healthcare workers should put in more time and effort at the time when the child is born. The parents should, from the start, be explained every option at their disposal. Only through a thorough knowledge of the disease and a working understanding of the options for treatment, and even cure, can the parents equip themselves to battle the effects of Thalassemia. The parents also need counseling to prepare them mentally on the things to come. Other than these two things, the parents also need physical training on how to handle the disease.

However, awareness also needs to be spread of the advantages of pre-marriage testing which can save greatly unnecessary sorrow.

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