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Original Research Article

Knowledge, attitude and practices of parents of thalassemic children undergoing treatment at thalassemia day care centre of pediatrics department, Govt. Medical College and Rajindra Hospital, Patiala

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ABSTRACT

Objectives: To explore the knowledge of the parents of thalassemic children, their attitude towards the prevention of birth of thalassemic children and practices followed by them in relation to treatment adherence.

Materials and Methods: Parents of 100 patients of Thalassemia, who were coming regularly for blood transfusion in Thalassemia day care centre at Rajindra Hospital, Patiala from January 2011 to Nov 2012, were interviewed regarding their knowledge about the inheritance and types of Thalassemia, prenatal diagnosis, various treatment options available and practices followed by them on a predesigned questionnaire. The variables were compared by Chi square test and results so obtained were analyzed using SPSS version 15 statistically.

Results: Knowledge of parents regarding importance of Ferritin levels, role of chelation therapy and Bone marrow transplantation in relation to age and sex of patients, their socioeconomic status was found statistically significant. Relation between knowledge of parents and treatment adherence, knowledge and attitude towards prevention of disease were found stastically significant. Relation of knowledge about treatment options available and effect on growth, behavior and studies was not found statistically significant.

Conclusion: A significant correlation has been found between knowledge about disease, treatment options available and prenatal diagnosis with treatment adherence and prevention of disease in future pregnancies.

Key Message: Community awareness programmes regarding Thalassemia and genetic councelling in high risk communities is the need of the hour.

1. Introduction

β-thalassemia is an autosomal recessive single gene disorder characterized by defective production of hemoglobin (Hb) and excessive destruction of Red Blood Cells. Hemoglobin is formed of four protein subunits, normally two α and two β. Genetic mutation in the gene encoding for β subunits of proteins, results in reduced or totally absent synthesis of β globin chain.[1]

Inadequate β globin chain production leading to decreased levels of normal hemoglobin (HbA) and unbalanced α and β globin chain production. In β-thalassemia, there is excess of α-globin chains relative to β and γ globin chains and α globin tetramers are formed. These inclusions interact with the red cell membrane and shorten red cell survival, leading to anaemia and increased erythroid production.

Mainstay of therapy of thalassemia major is transfusion therapy and management of its complications.

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Hypertransfusion remains the most accepted regimen in most parts of the world, in which the hemoglobin level above a minimum of 10 g/dl is maintained.

Repeated transfusions can lead to complications associated with iron overload which affects the heart, liver and endocrine glands mainly. Iron build-up is evaluated by measuring serum ferritin levels. When ferritin levels rise above 1000 μg/L, it's the time to start iron removing (chelation) therapy. Levels higher than 2500 μg/L over a period of 15 years are considered a risk factor for cardiac disease. Hence it is important to get serum ferritin levels at frequent intervals.[1]

Only definitive therapy available for thalassemia major which gives permanent cure is bone marrow transplantation, which is available at very few centres and cost is very high and is about 50,000 USD in developing countries.[2]

It has been estimated that more than 1,00,000 people are born every year all over the world with thalassemia and 10,000 in India alone. Prevalence of thalassemia in India is 3.3% in general population and 8-15% among certain communities and religions such as Sindhis, Punjabis, Khatris from North, Bengalis, Jains and Muslims.[3–5]

β thalassemia is a chronic illness that causes excessive psychological burden to children and their families. Thalassemia children have been described to show impaired abstract reasoning, deficits of language, attention, memory, constructional / visual spatial skills and executive functions, all of which are more prominent in hemosiderotic subjects.[2,6] A psychosocial support aimed at reducing emotional distress, improving the compliance to chelation therapy, and strengthening the coping strategies for a better integration in daily life is therefore necessary.[1]

Improvement of quality of patient care, reinforcement of medical education and enhanced efforts by clinical staff to provide practical knowledge to patients with thalassemia major should significantly improve patient's adherence to treatment.[7]

Although there is need to increase the community awareness of thalassemia, there is possibility that prenatal diagnosis and pregnancy termination will be accepted for the prevention of thalassemia.[8]

2. Aims and Objectives

1. To explore the importance of socio-demographic factors in predicting parents knowledge about thalassemia major.
2. To study knowledge regarding thalassemia disease in parents of thalassemic children.
3. To understand the relationship between disease knowledge and treatment adherence in thalassemia patients.
4. To study psychosocial problems in thalassemia affected families.
5. To study role of awareness about treatment options available in improving quality of life of thalassemia patients and prevention of birth of thalassemia children.

3. Material and Methods

The study was conducted on parents of 100 patients of thalassemia who were coming regularly for blood transfusion in Thalassemia Day Care Centre run by Patiala Thalassemic Children Welfare Association at Rajindra Hospital, Patiala.

3.1. Inclusion criteria

Diagnosed cases of thalassemia major.

Questionnaire has been drafted to suit the adult population and interview technique was adopted to fill the questionnaire.

3.2. Procedure

1. Study was conducted on parents of thalassemic children by interview technique.
2. The purpose of doing the study was explained to the parents and all of them will be requested to participate in the study.
3. The mother or father - whosoever was available - was interviewed to fill the questionnaire.
4. Data was analyzed statistically.

4. Observations

The parents were interviewed regarding their knowledge about the inheritance and types of thalassemia, prenatal diagnosis and various treatment options available and practices followed by them on a pre-designed questionnaire.

The patients were divided into 4 groups according to age i.e. 0-4years; 5-9years; 10-14years; ≥15 years, into 5 groups according to socio economic status i.e. I-upper class, II-upper middle, III-lower middle, IV-upper lower, V-lower after applying Kuppuswamy scale, into 3 groups on the basis of number of questions of knowledge correctly answered i.e. 0-5, 6-10, 11-15.

The variables were compared by Chi square test and results so obtained were analyzed using SPSS version 15 and level of significance was determined as its 'p' value with $p < 0.05$ taken as statistically significant.

Various possible levels of significance are:

1. $p > 0.05$ non-significant
2. $p < 0.05$ significant

In this study 25% of the patients were aged between 0-4 yrs, 28% between 10-14yrs, 13% above 15yrs of age and maximum numbers of patients were aged between 5-9yrs. Mean age of the patients was 8.36yrs. 66% were males and

44% were females. In this study, 38% of patients were from upper middle class and 38% were from upper lower class. 21% patients belonged to lower middle class, 2% to lower class and only !% belonged to upper class. In this study 57% of the patients were from urban area and 43% were from rural area. In this study maximum number of parents was from Khatri Community i.e. 41%, followed by Jatts (9%), Bazigars (9%) and Banias (7%). Family history of thalassemia was positive in 23% of the cases and history of consanguineous marriage was present in 4% cases only.

Age of diagnosis was 0-6 months in 63% of the cases, 7-12 months in 27% of cases and 10% cases were diagnosed between 1-3 years of age. Hundred percent of the patients were diagnosed within 3yrs of age.

41% of the parents knew that thalassemia is a type of blood disorder, 84% of the parents knew that thalassemia is a genetic disorder, 26% of the parents knew that there are three types of thalassemia, 57% knew the role of consanguinity and 76% of the parents had knowledge about the prenatal diagnosis that could be performed to prevent the birth of thalassemic children. Age related difference in their knowledge about these questions was found non-significant.

51% of the parents knew that this disease is manageable. 77% of parents knew that blood transfusion is needed for growth of the child and to maintain hemoglobin levels and 61% of the parents knew the role of the ferritin levels. 60% of the parents knew the role of chelation therapy, 43% knew about deferiprone, 48% about deferasirox and only 5% had knowledge about desferrioxamine. Seventy three percent knew about bone marrow transplantation, 42% knew about the surgery i.e. splenectomy and only 10% knew about the role of hydroxyurea. Maximum no. of patients whose parents knew about importance of ferritin levels, role of chelation therapy and bone marrow transplantation were 5-9yrs of age. Those who knew about DES had children above 15yrs of age. Knowledge of the parents regarding importance of ferritin levels, role of chelation therapy and option of the DES, BMT was related to age of the patient significantly.

Amongst the parents, who knew that thalassemia is a type of blood disorder 65.9% were parents of male children and 34.1% were parents of female children. Similarly amongst those who knew that thalassemia is a genetic disorder, there are 3 types of thalassemia, role of consanguinity, about prenatal diagnosis, curability of the disease and need for blood transfusion 67.9%,61.5%,68.4%,67.1%,68.6% and 63.6% were parents of male children respectively. Knowledge about the type of disease, genetic disorder, three types of thalassemia, prenatal diagnosis, curability of the disease, need for blood transfusion, importance of the ferritin levels, role of chelation therapy, bone marrow transplantation, surgery and role of hydroxyurea was not different significantly in relation to the sex of the patient. But knowledge about availability of deferiprone was more among the parents of male children and it was found statistically significant.

Out of 38 patients from upper middle class, 36 knew that it is a genetic disorder and out of 38, only 21 parents of upper lower class knew the same. Maximum number of parents who knew about inheritance of disease (42.9%), 3 types of thalassemia (69.2%), role of consanguinity (47.4%), prenatal diagnosis (46.1%), curability of the disease (62.7%) and need for blood transfusion (42.9%) were from upper middle class. Knowledge of the parents about these variables according to their socio-economic status was found to be statistically significant.

Maximum number of parents who knew the importance of ferritin levels (52.5%), role of chelation therapy (50%), options of DFP (60%), DFR (54.2%), about bone marrow transplantation (50.7%), surgery (61.9%) and role of hydroxyurea (70%) were from upper middle class. The difference in knowledge of the parents about importance of ferritin levels, role of chelation therapy, option of DFR, bone marrow transplantation and surgery was found to be statistically significant in relation to their socio-economic status.

Maximum percentage of parents who underwent prenatal diagnosis (40.6%) had children of 10-14 years of age. Maximum number of those who were willing for abortion of thalassemia affected foetus and who were adopting family planning method i.e.34.8% and 38.8% had children between 5-9 years of age. Difference in the attitude of the parents for adopting family planning method in relation to the age of the patients was statistically significant.

Amongst those who underwent prenatal diagnosis, who agree with performing abortion of thalassemia affected fetus and those who were adopting any family planning method 68.8%, 64.1%, 62.7% were parents of male children. As overall % age of male patients is more than that of female patients attitude of parents towards prevention of disease in relation with sex of the patients was not found to be statistically significant.

Amongst those who underwent prenatal diagnosis, agreed with abortion of thalassemia affected foetus and adopted family planning method, 68.8%, 59.9% and 62.7% were from urban area respectively. Attitude of parents towards prevention of disease in relation to geographical area was not found to be statistically significant.

Maximum number of the parents who were coming for regular follow up, monitoring ferritin levels of their children, whose children were using chelating agents, getting screened for HIV, HBsAg and HCV i.e. 39.2%, 45.2%, 45.9%, 38.4%, 49% and 48% were from upper middle class. Difference between treatment adherence of the parents in terms of regular follow up, monitoring ferritin levels, using chelating therapy and screening for HBsAg of their children in relation to their socio-economic status was found to be statistically significant**.**

Maximum number of parents who were coming for regular follow up, monitoring ferritin levels of their children, whose children were using chelating agents and were screened for HIV, HBsAg and HCV i.e. 48.5%, 56.2%, 56.7%, 51.2%, 58.8%, 60% were parents who gave 6-10 correct answers. Also 100% i.e. 21/21, 80.9% i.e. 17/21, 90.5% i.e. 19/21, 85.7% i.e. 18/21, 71.4% i.e.15/21, 66.7% i.e.14/21 of parents who gave 11-15 correct answers regarding disease knowledge were coming for regular follow up, monitoring ferritin levels of their children, using chelating agents and getting their children screened for HIV, HBsAg and HCV respectively. So relation of knowledge and treatment adherence was found statistically significant.

Lowest number of parents, who underwent prenatal diagnosis, was willing for abortion of thalassemia affected foetus i.e. 18.8% and 27.2% were those who answered 0 to 5 number of questions regarding knowledge. Maximum number i.e. 56.7% of parents adopting family planning methods were those who answered 6-10 number of questions regarding knowledge. Difference between attitudes of parents towards prevention of disease in relation to knowledge regarding disease was statistically significant.

Nineteen (25.3%) children out of 77 whose parents correctly knew about need for blood transfusion as against 11(47.8%) children out of 23, whose parents had incorrect or no knowledge had temper tantrums. 14(23.3%) children out of 60, whose parents knew about role of chelation therapy as against 16 (40%) out of 40, whose parents didn't knew, had temper tantrums. Only relation of knowledge about need for blood transfusion and chelating therapy in parents was statistically significant with presence of tamper tantrums. Relation of knowledge about treatment options available and effect on growth, behaviour and studies was not found statistically significant.

5. Conclusion

Knowledge of the parents of thalassemic children was inadequate as only 21% parents gave 11-15 correct answers regarding knowledge. Knowledge of the parents regarding importance of ferritin levels, role of chelation therapy and Bone marrow transplantation was related to age of the patients significantly. No significant difference was found in knowledge of parents in relation to sex of the patients. A significant correlation was found in the knowledge of parents and socioeconomic status. Parents from upper middle class had the maximum knowledge. Knowledge regarding disease and treatment options was more in parents from urban area. Significant correlation has been found between knowledge about disease, treatment options and prenatal diagnosis with treatment adherence. More positive attitude of parents towards prevention of disease was found in parents who answered maximum number of questions correctly.

6. Source of Funding

None.

7. Conflicts of Interest

There is no conflict of interest.

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