International Journal of Contemporary Pediatrics
Kumar N et al. Int J Contemp Pediatr. 2018 May;5(3):839-842
http://www.ijpediatrics.com
pISSN 2349-3283 | eISSN 2349-3291

DOI: http://dx.doi.org/10.18203/2349-3291.ijcp20181479

Original Research Article

Cross sectional study to assess behavioral problems in multi-transfused thalassemic children and psychosocial factors affecting them

Naresh Kumar[1], Jaspal Singh[2]*, Hira Khullar[2], Munish Arora[2]

[1]Department of Pediatrics, Sri Guru Ramdass Medical College and Research University, Amritsar, Punjab, India
[2]Department of Pediatrics, Government Medical College, Amritsar, Punjab, India

Received: 30 March 2018
Accepted: 09 April 2018

***Correspondence:**
Dr. Jaspal Singh,
E-mail: drjaspalsingh15@gmail.com

ABSTRACT

Background: Beta- thalassemia major is a chronic disorder of blood, having an extensive impact on the quality of life of the affected child and parents/caregivers. It involves lifelong management, with repeated blood transfusions and chelation therapy. With improved life expectancy owing to better medical facilities and education status of caregivers, psychosocial aspects of thalassemia are gaining importance. Objective of the present study was to assess the behavioral problems in multi- transfused thalassaemic children and psychosocial factors affecting them.
Methods: The study was conducted in a tertiary care level hospital having separate thalassemia day care centre. The study was a cross- sectional study involving 100 multi- transfused thalassaemic children of age 6-18years.Child Behavior Check List (Achenbach) (CBCL) was used to collect data from each parent regarding the child's behavior. Parental Attitude Scale (Rangaswamy 1989) was applied. Descriptive statistical analysis was used with analysis of variance (ANOVA) and Student's t test to find the significance of data.
Results: The CBCL total scores were high in 39% patients which indicated that behavior problems are more common in thllasemic patients. Higher CBCL scores were found in older children, those having poor school performance, with mothers who are illiterate, had history of death of thalassemic relative in family, longer duration of diagnosed illness, poor pre- transfusion hemoglobin level, and poor school attendance.
Conclusions: Behavioral problems are common in multi- transfused thalassaemic children. Timely diagnosis and appropriate remedial intervention of behavioral problems in these children would improve quality of life of these children.

Keywords: Behavioral problems, Child behavior check list, Multi- transfused thalassemia

INTRODUCTION

Thalassemia was first noted in the Mediterranean population wnd this geographical association explained its naming as "thalassa" which in greek means the sea and the "Haema" is Greek for blood. Thalassemia is an autosomal recessive haemolytic anaemia that results from defective production of haemoglobin due to mutation in the genes which directs the production of haemoglobin. Beta Thalassemia is the most common single gene disorder. Worldwide approximately 15 million people are estimated to suffer from thalassemic disorders and at here are about 240 million carriers of beta Thalassemia worldwide i.e. 1.5% of world population.

The burden of Thalassemia in India is very high with nearly 12000 infants being born every year with this disorder. Management of Thalassemia is lifelong which includes repeated blood transfusions and chelation. These children have more of negative self- concept when

compared to their normal counterparts.[1] However, data regarding the psychosocial aspects of thalassemia major are scanty and controversial.[2-5] In India, health care providers are more concerned with medical management of thalassemia, probably because till about two decades ago, the life span of thalassemic children was limited and the medical problems of the disease were so severe that all other aspects of the illness and its management were neglected. Now, with increased life expectancy and improvement in the medical management of thalassemia, the psychosocial and behavioral problems are coming to the forefront. Hence, this study was done to assess the behavioral problems in thalassemic children and the factors affecting them, so that not only physical well- being but also the mental and social well- being of a thalassemic child is achieved.

METHODS

The study was a cross- sectional study done on 100 multi- transfused thalassemic children aged 6-18 years, who are registered in the Thalassemia day care centre of the hospital. The children included in this study suffered from transfusion- dependent beta- thalassemia major and were not suffering from any other chronic medical illness. Cross- sectional design was preferred over prospective design due to logistic constraints as subjects visited once in 4-8 weeks and stayed only for a few hours, that is, for the duration of the blood transfusions.

Demographic profile and clinical data were recorded in a predesigned proforma.

Parents were interviewed during the inpatient stay. Child Behavior Check List (CBCL; Achenbach) translated to local language and standardized and Parental Attitude Scale (PAS; Rangaswamy 1989) were used.[6,7] CBCL is one of the most commonly used measures of child psychopathology which involves obtaining care giver's reports. There are 113 items scored 0-2 and the required time for administering the measure is 25-30 minutes. The instrument measures eight constructs or syndromes. This also allows examination of two broad syndromes: internalizing problems (social withdrawal, somatic complaints and anxiety, depression) and externalizing problems (delinquent behavior and aggressive behavior). Raw scores can be converted into age- standardized scores (T scores having a mean = 50 and SD = 10). Scores are interpreted as follows: For total problems, externalizing problems and internalizing problems, T scores less than 60 are considered in the normal range, 60–63 represent borderline scores and scores greater than 63 are considered in the clinical range. Rangaswamy, the author of Parental Attiude Scale states the attitudes of parents toward children who are disabled are usually negative. These reactions can be of shock, guilt, anger, rejection, depression or hostility. PAS scale is developed to measure the parental attitude towards their disabled or problematic children and It has 40 items spread equally in to above 8 areas. Higher the score, stronger the negative attitude of parents to child. Describe following parental attitudes-over protection, acceptace, rejection, permissiveness, communication, attitude towards education of the child, home management and hostility towards the child.

Statistical anlaysis

Descriptive statistical analysis has been carried out in the present study. Results on continuous measurements are presented on Mean±SD (min- max) and results on categorical measurements are presented as number (%). Significance is assessed at 5% level of significance. Analysis of variance (ANOVA) has been used to find the significance of study parameters between three or more groups of patients; Student's t test (two- tailed, independent) has been used to find the significance of study parameters on continuous scale between two groups (inter- group analysis) and Student's t test (two- tailed, dependent) has been used to find the significance of study parameters on continuous scale within each group.

RESULTS

Out of 100 children, 64(64%) were males. The mean age of the children was 9 years. Most 48 (48%) belonged to low socioeconomic status and 40 (40%) were from rural origin. Father's education was more than 8 years in 42 (42%) cases, whereas 36 (36%) of the mothers were educated for more than 8 years (Table 1).

Table 1: Patients profile and other details.

??	???	???	P-value
Age			
>9 years	42	50.90±5.59	<0.001
<9 years	58	64.86±8.05	
School performance			
Good	40	51.15±4.01	<0.001
Bad	60	64.32±5.98	
Fathers education			
>8 years	42	58.86±7.79	0.008
<8 years	58	61.88±8.97	
Mothers education			
>8 years	36	39.98±9.15	0.006
<8 years	64	68.37±8.98	
Duration of diagnosed illness			
>5 years	80	63.48±8.97	0.001
<5 years	20	53.26±4.76	
Average weeks of absence from school			
>8	40	66.32±5.12	<0.001
<8	60	54.89±6.92	
Recent hemoglobin levels			
>10 gm%	52	55.32±7.84	<0.001
<10 gm%	48	68.96±2.97	
Duration of illness			
>5 years	80	61.87±9.18	<0.001
<5 years	20	52.86±4.64	

Fourteen children (14%) had siblings suffering from the same disease. Only 10 (10%) children had history of death of a relative due to thalassemia. Eighty children (80%) were suffering for more than 5 years (Table 1). And 56 (56%) of them had already received more than 40 blood transfusions and 52 (52%) had good pre- transfusion hemoglobin percentage (>10 g%). 40 (40%) of them were absent to school for more than 8 weeks (Table 1).

Table 2: Distribution of CBCL total scores (T scores).

Scores	Number (%)	95% CI
<60	48 (48)	34.80-61.49
60-63	13 (13)	11.24-33.04
>63	39 (39)	20.78-45.81
Total	100 (100)	

In the present study, it was found that 39% of thalassemic children had clinically abnormal high CBCL total scores, indicating the presence of behavioral problems in them (Table 2). Clinically significant, abnormal CBCL Internalization problem scores were seen in 41% children, indicating symptoms of social withdrawal, somatic complaints, and anxiety/depression (Table 3).

Table 3: Distribution of CBCL internalization problem scores.

Scores	Number (%)	95% CI
<60	45 (45)	28.64-53.22
60-63	1 4 (14)	12.87-37.45
>63	41 (41)	25.14-55.56
Total	50 (100)	

Clinically significant, abnormal CBCL Externalization score was seen in 37% of them, indicating delinquent and aggressive behaviour symptoms (Table 4).

Table 4: Distribution of CBCL externalization problem scores.

Scores	Number (%)	95% CI
<60	41 (41)	31.67–55.49
60-63	22 (22)	14.17–36.96
>63	37 (37)	29.10–48.73
Total	100 (100)	

Statistically significant higher CBCL scores were associated with children of older age group (>7 years), those with poor school performance, longer duration of diagnosed illness (>5 years), lower recent Hb% (<10 g%), and greater duration of absence from school (>8 weeks). Higher prevalence of internalizing problems in our study is similar to the study by Pradhan et al. in which they had reported that symptoms of sadness and disinterest were more common with thalassemia. In the present study, older children had higher CBCL scores and thus had more behavioral problems. Many children had prolonged absence from school and poor school performance, due to the need for frequent blood transfusions. In low income families, expenditure on the child's illness was high, the children had more behavioral and psychosocial problems. Level of parents' education also had a significant effect on their attitudes toward the ill child and the compliance to treatment and hence on the behavior of the child. It was further observed that highly educated mothers had overprotective attitudes toward their ill children as per Parental Attitude Scale and hence these children had more behavioral problems. It was also found that longer duration of illness and presence of systemic complications of thalassemia were associated with higher CBCL total scores, indicating more behavioral problems.

DISCUSSION

Prevalence of behavioral disorders among thalassemic children in past studies ranged from 23 to 80% and they adversely affect compliance to treatment in thalassemia.[8-12] In the present study, it was found that 39% of thalassemic children had abnormal CBCL total scores. Study by yalen et al. in Turkey had also revealed that older age (>12 years), higher education of mothers and poor school performance were associated with higher risk of behavioral problems.[13] In this study, 39% had behavioral problems and 60% had poor school performance which is similar to the results of a study in South Turkey where 31% of thalassemic children had anxiety disorders and 60% had poor school performance.[6] The childhood psychological problems among thalassemic children were similar to that seen in other chronic physical illnesses but had been neither recognized nor treated.[14] This study is one among the few Indian studies which have tried to assess the presence of behavioral problems in multi- transfused thalassemic children using CBCL. There are some limitations to this study. The checklist was completed by the interviewing the parents of the patients and this evaluation was done while the child was undergoing blood transfusion. The thoughts and emotions of the parents could have influenced the results. Also, there was no control group in the study.

CONCLUSION

The present study shows that behavioural problems prevalence is very high in multitransfused thalassaemic children. Therefore, the periodic assessment of these children for any psychiatric morbidity will help in early diagnosis and treatment. Hence it would improve the mental health and would make them cope with thalassemia and its complex and lifelong management regimen and hence have a better quality of life.

Funding: No funding sources
Conflict of interest: None declared
Ethical approval: The study was approved by the Institutional Ethics Committee

REFERENCES

1. Moorjani JD, Issac C. Neurotic manifestations in adolescents with thalassemia major. Indian J Pediatr 2006;73:603- 7.
2. Canatan D, Ratip S, Kaptan S, Cosan R. Psychosocial burden of beta- Thalassemia major in Antalya, South Turkey. Soc Sci Med 2003;56;815- 9.
3. Ratip S, Modell B. Psychological and sociological aspects of the Thalassemias. Semin hematol 1996;33:53- 65.
4. Aydinok Y, Erermis S, Bukusoglu N. Psychosocial implications of Thalassemia Major. Pediatr Int 2005;47:84- 9.
5. Zani B, Di Palma A, Vullo C. Psychosocial aspects of chronic illness in adolescents with Thalassemia Major. J Adolesc 1995;18:387- 402.
6. Achen B. Mannual for the child behavior checklist 14- 18 and 1991 profile, Burlington, VI; University of Vermount, Department of Psychiatry. 1991.Available at http://www.checklist.vvm.edu. Last accessed on 2010 March 02.
7. Rangaswami K. Parental attitude towards mentally retarded children. Indian J Clin Psychol. 1995;22:20- 3
8. Sherman M, Koch D, Giardina P, Seigel P, Siegel R, Shapiro T. Thalassemic children's understading of illness: A study of cognitive and emotional factors. Anns N Y Acad Sci. 1985;445:327- 36.
9. Shaligram D, Girimaji SC, Chaturvedi SK. Psychological problems and quality of life in children with Thalassemia. Indian J Pediatr. 2007;74:727- 30.
10. Chandra SJ, Goswami U, Singh V, Dutta A. Case control study of psychosocial morbidity in B thalssemia major. J Paediatr. 2007;50:516- 20.
11. Beratis S. Psychosocial status in preadolescent children with B thalassemia. J Psychosom Res. 1993;37:271- 9.
12. Pradhan PV, Shah H, Rao P, Ashturkar D, Ghaisas P. Psychopathology and self-esteem in chronic illness. Indian J Pediatr 2003;70:135- 8.
13. Yalçn SS, Durmuşoğlu-Sendoğdu M, Gümrük F, Unal S, Karg E, Tuğrul B. Evaluation of the children with Beta- Thalassemia in terms of their self- concept, Behavioural and Parental Attitudes. J Pediatr Hematol Oncol. 2007;29:523- 8
14. Khurana A, Katyal S, Marwaha RK. Psychosocial burden in Thalassemia. Indian J Pediatr. 2006;73:877- 80.

Cite this article as: Kumar N, Singh J, Khullar H, Arora M. Cross sectional study to assess behavioral problems in multi-transfused thalassemic children and psychosocial factors affecting them. Int J Contemp Pediatr 2018;5:839-42.