Study of behavioral problems in multi-transfused thalassemic children

Chandrashekar Hongally, Benakappa Asha D.1, Shankar Reena¹
Departments of Psychiatry and ¹Paediatrics, Bangalore Medical College and Research Institute, Victoria Hospital, Bangalore, Karnataka, India

ABSTRACT

**Background:** Beta-thalassemia major is a chronic disorder of blood, having an extensive impact on the affected child. It involves lifelong therapeutic regime, with repeated blood transfusions. With improved life expectancy, due to improved medical management psychosocial aspects of thalassemia are gaining importance.

**Objective:** To assess the behavioral problems in multi-transfused thalassemic children and psychosocial factors affecting them.

**Setting:** The study was conducted in a tertiary care level hospital and research institute catering mainly to a population of low socioeconomic status.

**Design:** The study was a cross-sectional study involving 50 multi-transfused thalassemic children of age 5–10 years.

**Materials and Methods:** Fifty multi-transfused thalassemic children, aged 5–10 years, not suffering from any other major medical illness, were included. 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 32% patients, indicating the presence of behavioral problems. Higher CBCL scores were found in children of older age group, those with poor school performance, whose mothers’ education was more than eighth standard, had history of death of thalassemic relative in family, greater duration of diagnosed illness, poor pre-transfusion hemoglobin level, and who had longer periods of school absenteeism.

**Conclusions:** Behavioral problems are common in multi-transfused thalassemic children. Early diagnosis and intervention of behavioral problems in these children would make them cope with thalassemia better.

**Key words:** Behavioral problems, child behavior check list, multi-transfused thalassemia

INTRODUCTION

Beta-thalassemia major is a chronic disorder of blood, having an extensive impact on life and presenting with hemolytic anemia, growth retardation, hepatosplenomegaly and skeletal abnormalities. It often requires regular blood transfusions, iron chelation therapy and sometimes splenectomy for its management.[1] Thus, the therapeutic regime is complex, lifelong and inconvenient, requiring repeated hospitalizations and blood transfusions, which often affects the child’s physical and mental health negatively.[2]

It is expected that these children are at high risk of developing behavioral and psychosocial problems like opposition, passiveness, anxiety, phobias and depression, which affect their self-confidence and give rise to emotions and thoughts which negatively affect their quality of life and compliance to therapy.[3] Many of the thalassemic children experience fear related to intravenous line insertion and subcutaneous infusion pumps. Children with thalassemia in the pre-school and latency age groups are usually anxious and excessively dependent on their parents.[4] They display psychosomatic symptoms and are frequently absent.
from school. Thalassemic children have more of negative self-concept when compared to their normal counterparts.\[3\]

However, data regarding the psychosocial aspects of thalassemia major are scanty and controversial.\[6-9\] In India, only medical management of thalassemia is the concern even today, probably because till about two decades back, 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 dramatic improvement in the medical management of thalassemia, the psychosocial and behavioral problems in these children and their recognition and management at an early stage are coming to the forefront. Hence, this study has been undertaken to assess the behavioral problems in thalassemic children and the factors affecting them, so as to emphasize on the importance of achieving not only physical well-being but also the mental and social well-being of a thalassemic child.

**MATERIALS AND METHODS**

The study was a cross-sectional study done on 50 multi-transfused thalassemic children aged 5–10 years, who are registered in the Thalassemia ward of the hospital. The children included in this study suffered from transfusion-dependent beta-thalassemia and had no 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 collected using a semi-structured proforma. Parents were interviewed during the inpatient stay. Child Behavior Check List\[10\] (CBCL; Achenbach) translated to local language and standardized and Parental Attitude Scale\[11\] (PAS; Rangaswamy 1989) were used. 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 Attitude 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.\[11\] Describe following parental attitudes-over protection, acceptance, rejection, permissiveness, communication, attitude towards education of the child, home management and hostility towards the child.

**Statistical methods**

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 50 children, 28 (56%) were males. The mean age of the children was 7 years. Most 29 (58%) belonged to low socioeconomic status and 25 (50%) were from rural origin. 21 (42%) were having income less than INR 3000. Sixty percent had more than INR 1000 spent as expenditure for the illness per annum.

Father’s education was more than 8 years in 21 (42%) cases, whereas 18 (36%) of the mothers were educated for more than 8 years [Table 1].

Seven children (14%) had siblings suffering from the same disease. Only 5 (10%) children had history of death of a relative due to thalassemia.

Forty children (80%) were suffering for more than 5 years [Table 1]. And 28 (56%) of them had already received more than 40 blood transfusions and 26 (52%) had good pre-transfusion hemoglobin percentage (>10 g%). 20 (40%) of them were absent to school for more than 8 weeks [Table 1].

In the present study, it was found that 32% 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 34% children, indicating symptoms of social withdrawal, somatic complaints, and anxiety/depression [Table 3]. Clinically significant, abnormal CBCL Externalization score was seen in 30% of them, indicating delinquent and aggressive behaviour symptoms [Table 4].
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.[14]

In the present study, it was found that older children had higher CBCL scores and thus had more behavioral problems. Many children had long periods of absence from school and poor school performance due to the illness, its complications and due to the need for frequent blood transfusions, and these children had more behavior problems.

In families where the income was low and expenditure on the child’s illness was high, the children had more behavioral and psychosocial problems. Parents’ education also had a strong effect on their attitudes toward the ill child and the compliance to treatment and hence on the child’s behaviors. It was found that higher 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

Studies over the past 25 years have shown that prevalence of behavioral disorders among thalassemic children ranged from 23 to 80%,[12-16] and these psychological disturbances adversely affect compliance to treatment in thalassemia.[15]

In the present study, it was found that 32% of thalassemic children had clinically 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.[1] In this study, 32% had behavioral problems and 60% had poor school performance which is similar to the results of a study in South Turkey[6] where 31% of thalassemic children had anxiety disorders and 60% had poor school performance. The childhood psychological problems among thalassemic children were similar to that seen in other chronic physical illnesses but had been neither recognized nor treated.[13]

This study is one among the few Indian studies which have tried to assess the presence of behavioral problems in multi-transfused thalassemic children, especially in the pre-adolescent age group, using CBCL.

There are some limitations to this study. The checklist was completed by the parents of the patients and this evaluation was done while the child was undergoing blood transfusion. So, it could have been influenced by the parents’ emotions and thoughts at that moment. There was no control group in the study.

### CONCLUSION

The present study shows that there is a high prevalence of behavioral problems in multi-transfused thalassemic
children. Hence, it is important to periodically assess these children for any psychiatric morbidity. Early diagnosis and treatment of behavioral problems in these children would make them cope with thalassemia and its complex and lifelong management regimen and hence have a better quality of life. We suggest long-term interventional follow-up studies to prove the hypothesis.

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