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Study of behavioral problems in Thalassemia major children from 6 year to 18 years of age at CRGH and associated hospitals of RD Gardi medical college Ujjain (MP).

Shatanshi Shukla*, Mamta Dhaneria

Department of Pediatrics, RD Gardi Medical College, Ujjain, India

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Abstract

Background: Thalassemias are a heterogeneous group of genetic disorders that result from a decreased synthesis of alpha or beta chains of Hemoglobin (Hb). Hemoglobin serves as the oxygen-carrying component of the red blood cells. It consists of two proteins, an alpha, and a beta. If the body does not manufacture enough of one or the other of these two proteins, the red blood cells do not form correctly and cannot carry sufficient oxygen; this causes anemia that begins in early childhood and lasts throughout life.

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. There are many researches done regarding the clinical profile in thalassemia patients but there was no study done the behavioral problems and psychological problems in thalassemia major patients in central India especially Ujjain in MP. Hence, this study was done to assess the behavioral problems in thalassemia children and the factors affecting them.

Material and Methods: This cross-sectional study was done on thalassemia major children who are registered for regular blood transfusion at the thalassemia ward of CRGH between January 2019 to February 2020. Children whose parents/attending guardians who do not give consent were excluded from the study. Total 180 thalassemia patients were enrolled between 6 years and 18 years of age group. All patients had undergone CBCL scoring system which is child behavior checklist. Total 113 questionnaire were asked to parents and/or adolescent patients who could understand various questions. The patients were divided according to their behavioral problems which were classified as internalizing problems and externalising problems. All Statistical analysis done with the help of statistical software SPSS 21.0 version.

Results: Prevalence of behavioral problems increase when age increase (p value=0.000). Prevalence of behavioral problems was directly correlated with bad (poor) scholastic performance (p=0.000). More duration of illness was associated with prevalence of behavioral problems in 15.7% thalassemic children (p=0.000). 42.8% had bad (poor) scholastic performance. 38.9% had >3 years duration of illness. 41.1% thalassemic children had more duration of school absenteeism. 83.9% had CBCL score (t score) <65 that is they did not have any behavioral problems. 10.0% had CBCL score between 65-70 that means they were suffering from borderline behavioral issue. 6.1% had CBCL total score >70that means having clinically significant behavior problems.

Conclusion: The present study shows that behavioral problems prevalence is very high in patients with multitranfused thalassemia major. Therefore 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 a better quality of life.

Keywords: *Thalassemia, Behavioral problems, CRGH, CBCL.*

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Introduction

Thalassemias are a heterogeneous group of genetic disorders that result from a decreased synthesis of alpha or beta chains of Hemoglobin (Hb). Hemoglobin serves as the oxygen-carrying component of the red blood cells. It consists of two proteins, an alpha, and a beta. If the body does not manufacture enough of one or the other of these two proteins, the red blood cells do not form correctly and cannot carry sufficient oxygen; this causes anemia that begins in early childhood and lasts throughout life.

Thalassemia is an inherited disease, meaning that at least one of the parents must be a carrier for the disease. It is caused by either a genetic mutation or a deletion of certain key gene fragments [1].

In India, every year 10,000 children are being born with thalassemia which approximately accounts for 10% of the total world incidence of thalassemia-affected children [2] and one in eight of thalassemia carriers live in India. The prevalence of thalassemia ranges between 0.6% and 15% across south India [3]. Behavioral problems in children with thalassemia major: The hereditary nature of this disease, changes in appearance, and need for continuous treatment, impose unfavorable psychological impacts on patients and their families [4,5]. Patients with thalassemia are prone to various psychological disorders [6,7].

According to the findings of a study in Iran, 44% of the children affected by thalassemia major had anxiety and depression and 74% had a low quality of life [8]. Thalassemic children are forced to acknowledge differences between themselves and others which are associated either to the physical dimension (facial appearance, stunted growth, bone deformities) or their inability including lack of energy to accomplish daily tasks and prior physical activities that used to enjoy [8,9]. The chronicity of the disease affects negatively children social life because it reveals the disease, triggers comments or questions in their environment, mainly the school. Usually, thalassemic children refuse to discuss their health problem with friends and dependent on parents.

It is worth noting that each child has different ways of facing stressful experiences including chronic illness. The different responses depend on their personal characteristics, age, stage of cognitive development, adaptability, previous experiences of illness, etc. [8,10,11]. All factors mentioned above, have deleterious effects on children's self- esteem, personality development and emotional health. Usually children develop negative thoughts about their lives, feelings of loneliness, isolation and psychiatric morbidity that make harder their integration into social environment [12,13].

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 [14]. There are many researches done regarding the clinical profile in thalassemia patients but there was no study done the behavioural problems and psycological problems in thalassemia major patients in central India especially Ujjain (MP). Hence, this study was done to assess the behavioral problems in thalassemic children and the factors affecting them, so that not only physical wellbeing but also the mental and social well-being of a thalassemic child is achieved and the patients of thalassemia major can achieve their full potential.

Aim and objectives

To study the behavioural patterns and its associated risk factors in thalassemia major patients admitted in pediatric In-Patient Department (IPD) at CR Gardi Hospital associated with RD Gardi medical college Ujjain (MP)

Materials and Methods

This cross-sectional study was done on 180 Thalassemia major children who are registered for regular blood transfusion at the Thalassemia ward of CR Gardi Hospital associated with RD Gardi medical college Ujjain between January 2019 to February 2020.

Inclusion criteria: 1. Children diagnosed with transfusion-dependent beta-thalassemia and

2. Having no other chronic medical illness were included in the study.

Exclusion criteria: Children whose parents/attending guardians who do not give consent.

The Child Behavior Checklist (CBCL) is a component of the Achenbach System of Empirically Based Assessment (ASEBA). The ASEBA is used to detect behavioral and emotional problems in children and adolescents. CBCL is one of the most commonly used measures of child psychopathology which involves obtaining care giver's reports. For translation into local language (Hindi) WHO guidelines are followed. These include translation from English to Hindi by two subject-pediatrics expert and language expert. There are 113 items scored 0–2 and the required time for completing is 30-35 minutes. The instrument measures eight constructs or syndromes. This also allows examination of two broad syndromes:

1. **Internalizing problems:** a. Social withdrawal b. Somatic complaints c. Anxiety d. Depression.

2. **Externalizing problems:** a. Oppositional problems b. Conduct problems.

Raw scores can be converted into age-standardized scores (T scores having a mean=50 and SD=10) by using standard tables provided with the manual of CBCL.

Statistical Method

All Statistical analysis done with the help of statistical software SPSS 21.0 version. Descriptive statistical analysis has been carried out in the present study. Results on continuous measurements are presented on mean ± SD and results on categorical measurements are presented as number (%). Chi-Square test has been applied to find association between categorical variables. 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 has been used to find the significance of study parameters on continuous scale between two groups. Significance is assessed at 5% level of significance.

Descriptive statistics is used to calculate the prevalence for total behavioral problems ie both internalising and externalising problems.

Sample size: To calculate the sample size based on the prevalence with 95% confidence level, we can use the following formula:

n= z2*P*(100-P)/d2

Where, z= 1.96 at 95% confidence interval

P= 67% (prevalence of anxiety-related symptoms was present in 67% which has been taken from ref. no….)

d=Relative error=10%

n=(1.96*1.96)*67*(100-67)/6.7*6.7

n=190 Children with Thalassemia.

Observation and Results

In the present study out of total 180 patients enrolled, 105(58.3%) are males and 75(41.7%) are females. Maximum no. of cases is <7 years of age group 98 (54.4%) while 82(45.6%) cases are >7 years of age group (Table 1).

Total score category	No. of patients (n)	%	Total score category
<65	151	83.9	<65
65-70	18	10	65-70
>70	11	6.1	>70

Table 1. Distribution of total CBCL score in the study group.

Above table shows that distribution of study group and CBCL total score where n=151(83.9%) are having <65 CBCL total score, which is in normal range, n=18(10.0%) are having CBCL total score 65-70 which is in borderline range, while n=11(6.1%) are having CBCL total score >70 which is in clinical range. Prevalence of behavioral problems in study group is 6.1% (n=11) (Table 2).

		Total score category						Chi square	P value
		<65		65-70		>70			
		N	%	N	%	N	%		
Age in groups	≤ 7 years	94	95.9	4	4.1	0	0		
	>7 years	57	69.5	14	17.1	11	13.4	24.392	0

Table 2. Distribution of the study group showing correlation between age and CBCL total score (T score).

Above table shows that significant correlation is observed between age groups and CBCL total score categories. Among >7 years of age groups n=11(13.4%) CBCL total score (T-score) is >70 which is significantly higher as compared to <7 years age groups n=0 (0.0%). As the age group increases prevalence of behavioral problems increase which is also statistically highly significant (chi-square=24.392, p value 0.000) (Tables 3 and 4).

Variables		N	Mean total score	SD	T	P value
Age Groups	≤ 7 years	98	42.71	10.79	6.237	0
	>7 years	82	54.12	13.74		
Gender	Male	105	46.18	12.66	2.06	0.041
	Female	75	50.33	14.22		
Religion	Hindu	151	48.11	13.38	0.442	0.659
	Muslim	29	46.9	14.04		
Residence	Rural	120	48.72	13.83	1.137	0.257
	Urban	60	46.3	12.62		
School performance	Good	57	41.7	9.56	18.884	0

	Average	46	44.98	12.51		
	Bad	77	54.26	13.61		
Duration of illness	≤ 3 years	110	43.17	11.01	6.588	0
	>3 years	70	55.36	13.64		
Average weeks of absence from the school	<8 weeks	106	43.37	10.92	0	0
	>8 weeks	74	54.42	14.12		
Total		180	47.91	13.45		

Table 3. Comparison of mean total score with different study variables.

Variables		N	Mean depressive problem score	SD	t	P-value
Age Groups	≤ 7 years	98	8.18	3.93	4.696	0
	>7 years	82	11.2	4.68		
Gender	Male	105	9.18	4.36	1.316	0.19
	Female	75	10.08	4.74		
Religion	Hindu	151	9.76	4.45	1.396	0.16
	Muslim	29	8.48	4.87		
Residence	Rural	120	9.78	4.58	0.954	0.34
	Urban	60	9.1	4.43		
School performance	Good	57	7.89	3.33	10.249	0
	Average	46	8.89	4.81		
	Bad	77	11.18	4.63		
Duration of illness	≤ 3 years	110	8.35	4.03	4.757	0
	>3 years	70	11.46	4.62		
Average weeks of absence from the school	<8 weeks	106	8.36	3.91	4.462	0
	>8 weeks	74	11.27	4.82		
Total		180	9.56	4.53		

Table 4. Comparison of mean depressive problem score with different study variables.

Discussion

Thalassemia is a chronic disease which has both physical and psychological consequences. The high prevalence of psychological disorders is predictable due to physical disabilities and social impairments in patients with β-thalassemia. High prevalence of behavioral and psychological disorders can be associated with a decrease in the self- esteem of patients and completely alter the person's self-concept [15].

In present study,maximum cases are ≤ 7 years of age group n=98(54.4%) while n=82(45.6%) cases are >7 years of age group. Mean age of patients in present study is 8.36 ± 2.281 (Table 2). Similar to present study in the study by Fouzia et al. [16], the mean age of the patients was 9.5 ± 5.1 years, median age of the patients being 8.6 years.

In present study out of total 180 patients enrolled, n=105(58.3%) are males and n=75(41.7%) are females. This shows that more male children are affected than female children in the present study (Table 3). Similar, male preponderance was reported by studies from Bangladesh and India. [17,18] In the present study out of 180 patients enrolled, n=76(42.2%) of patients belong to upper lower class, n=62(34.4%) belong to lower middle class while n=18(10%) belong to upper middle class according to modified kuppuswamy scale.

In present study, out of 180 patients enrolled, n=57(31.7%) have good school performance while n=46(25.6%) have average school performance and n=77(42.8%) have poor scholastic performance. Similar to present study, Yalen et al.

[19] in Turkey had also revealed that poor school performance was associated with higher risk of behavioral problems. In present study out of 180 patients enrolled, n=110(61.1%) majority have <3 years duration of illness while n=70(38.9%) have >3 years duration of illness. According to Chandrashekar et al. [14] in 2012, duration of illness >5 years in 40(80%).

In the present study, out of 180 patients enrolled 41.1 % had 8 weeks of school absenteeism as compared to 58.9% who had <8 weeks of school absenteeism. Child Behavior Check List (Achenbach) (CBCL) was used to collect data from each parent regarding the child's behavior. 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 30-35 minutes. In present study CBCL total score where n=151(83.9%) are having <65 CBCL total score, which is in normal range, n=18(10.0%) are having CBCL total score 65-70 which is in borderline range, while n=11(6.1%) are having CBCL total score >70 which is in clinical range. This is because the maximum number of patients were having total duration of illness <3 years (61.1%). Only 38.9% patients have >3 years duration of illness. Therefore the internalizing and externalizing problem manifest as CBCL score >70 were explicitly present in 6.1% of patients while 10% were in borderline range of 65-70. In the similar study by Chandrashekar et al. [14], in 2012, it was found that 32% of thalassemic children had clinically abnormal CBCL total scores which are higher than the present study.

In the present study significant correlation is observed between age groups and CBCL total score categories. Among >7 years of age groups 13(15.9%) CBCL total score (T score) is >70 which is significantly higher as compared to ≤ 7 years age groups 2(2.0%). This shows that as the age increases prevalence of behavioral problems increase which is also statistically highly significant (p value 0.000, chi-square=24.392.

In the present study significant correlation is observed between gender and CBCL total score categories, in females 7(9.3%) cases have >70 CBCL total score which is slightly higher when compared to male 4(3.8%) cases in the same category And the value is statistically insignificant (p value 0.118, chi-square=4.272).

In the present study significant correlation is observed between school performance and CBCL total score categories .Among bad school performance group 11(14.3%) have>70 CBCL total score which is significantly higher as compared to average and good school performance group. Prevalence of behavioral problems is associated with bad scholastic performance which is statistically highly significant (chi-square=23.307, p value 0.000). In the study by Chandrashekar et al. [14], in 2012, 32% had behavioral problems and 60% had poor school performance.

In the present study significant mean CBCL total score difference is observed between two age groups (t=7.93), mean total score is found higher in >7 years age group (64.03 ± 6.77) as compared to <7 years age group (56.102 ± 7.55).

The data is highly significant statistically (p value=0.000). In the present study, significant association was found between gender and prevalence of behavioral problems, female (50.33± 14.22) male (46.18 ± 12.66) (p value=0.041).

In the study by Naresh Kumar et al. [20], in 2018, statistically significant higher CBCL scores were associated with children of older age group (>7 years). It was found that older children had higher CBCL scores and thus had more behavioral problems. Which is similar to the present study? In contrast to present study, a study done by Naderi et al. [21] found no significant relationship between age and the prevalence of psychological disorders in patients with thalassemia.

In the present study significant mean CBCL total score difference is observed between school performance and (t=18.884) mean total score, found higher in bad scholastic performance group (54.26 ± 13.61) as compared to good performance group(41.70 ± 9.56). This observation is highly significant statistically (p value=0.000).

In a study done by Seyed Mohamad Kazem Nourbakhsh et al. [15], in 2021, The presence of behavioral problem was independent to gender (p=0.842),contrary to present study(p value 0.041). In the present study significant mean CBCL depressive problem score difference is observed between school performance (t=18.884), Mean depressive problem score found higher in the group who had bad scholastic performance (54.26 ± 13.61) as compared to good school performance group (41.70 ± 9.56) and the data is highly significant statistically (p value 0.000). In the present study significant mean CBCL anxiety problem score difference is observed between ≤ 7 years and >7 years age groups (t=3.766).Mean anxiety problem score is found higher in >7 years age group (5.33 ± 2.85) as compared to ≤ 7 years age group 4.04 ± 1.67 and the data is highly significant statistically (p value=0.000).

Limitation of the present study was that there is*:*

- No control group,
- No socioeconomic status.
- No education of parents taken into consideration.
- No Hb% was taken into consideration.

Conclusion

The present study shows that behavioral problems prevalence is very high in patients with multi tranfused thalassemia major. Therefore 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 a better quality of life.

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*Correspondence to:

Shatanshi Shukla

Department of Pediatrics

RD Gardi Medical College

Ujjain, India

E-mail: Shukla@gmail.com