

Psychosocial Illness In Children With Thalassemia: A Case-Control Study

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Abstract

Objective: To assess the psychosocial illness in children with thalassemia and to compare these problems in children with and without Thalassemia.

Materials and Methods: In this Case-Control study conducted at The Children's Hospital and the Institute of child health, Multan. From January to September 2021, 50 children with Thalassemia and 50 normal children were enrolled as case & control according to inclusion and exclusion criteria. After approval from the institutional ethical committee, detailed history, Socioeconomic status, educational status of parent and child, age of diagnosis of disease, and whether thalassemia is well controlled or not and complications were noted. A Paediatric Symptom Checklist was used for psychosocial problems in all children. Data were analyzed by using SPSS version 22. Mean and standard deviation for quantitative data, while frequencies and percentages for qualitative data were calculated. The P-value was calculated by the Chi-square test. The prevalence ratio (ODDS ratio) with a 95% confidence interval of all variables was calculated.

Results: Out of 100 patients 50 were in the case group (Thalassemia) and 50 control (non-thalassaemic Male female ratio was 1.2:1. 60% (n=30) of cases, and 78% (n=39) of control patients were age ranges between 5 to 10 years. The educational level of parents of 40% (n=20), and 56% (n=28) was below matric, and 42% (n=21) and 90% (n=45) of patients were going to school in the case and control groups respectively. 82% (n=41) of patients belonged to low socioeconomic status in each group. Regarding characteristics of thalassemia, 74% (n=37) of patients were diagnosed within 1st year of life, while 26% (n=13) were after 1st year. 64% (n=32) had well controlled and 36% (n=18) poor controlled disease. 20% (n=10) had developed Diabetes mellitus, 2% (n=1) heart failure, 74% (37) growth failure, 76% (n=38) hemolytic facial features, and 72% (n=36) skin discoloration. Psychosocial problems were statistically significant in children with Thalassemia as compared to healthy ones (p-value < 0.001). Poorly controlled thalassemia and complications of heart and growth failure were found statistically significant risk factors.

Conclusion: Psychosocial problems are common in children with thalassemia as compared to healthy ones. So, these patients must be referred for detailed psychological evaluation and management along with medical treatment.

Keywords: Psychosocial problems, Intellectual issues, Thalassemia children, Paediatric symptom checklist.

Introduction

B-Thalassemia is a most common, autosomal recessive genetic disorder, caused by a mutation of a single gene, which results in impaired globin chain synthesis leading to ineffective erythropoiesis, hemolysis, and chronic anemia.¹ It is a serious public health problem worldwide, especially in the Mediterranean region, 95% of birth with hemoglobin deficiency occurs in the Middle East, Indian subcontinent, Central and Southeast Asia, and large parts of Africa.² Although the exact date of the disease in Pakistan is not known, it is sharing the highest thalassemia burden. The distribution of the thalassemia gene in the Pakistani population is not random and restricted mostly to the affected families where intermarriages are common, leading to gene entrapment and proliferation. Therefore, mass screening is neither cost-effective nor a practical strategy for a country like Pakistan.³ The commonly quoted figure for the country is 100,000 transfusion-dependent thalassemic patients, which creates a heavy burden on resource-constrained national healthcare system.³

Although Thalassemia Patients are presented with variable degrees of anemia and extramedullary hematopoiesis resulting in bone changes, impaired growth, and iron overload. Psychosocial problems are also frequently seen not only in thalassemia children but the whole family, most common are depression anxiety, and intellectual, emotional, and behavioral Disorders 4. Beta-thalassemia major affects the emotional status, daily activities, family experiences, and occupational capabilities of patients and their caregivers due to the complex and heavy lifelong treatment protocol 5. Children with chronic hematological disorders can be exposed to anxiety and depression due to social problems such as separation from the family, limited social activity, physical and emotional deformities, death anxiety, and limitations in school activities and play 4. There are studies of early psychological maturity in children with a chronic disease that they cope with the psychological and medical consequences of this disease 6Thalassemia patients must be managed by a multidisciplinary approach with a special focus on psychosocial disorders to improve the quality of life of the whole family. Specialized interventional programs must be designed for patients, their siblings, and families with chronic illnesses like thalassemia.⁷

There are not so much data available about this problem, that's why a study was planned. The aim of this study is to identify the psychosocial problems in children with Thalassemia and to compare these problems in children with and without Thalassemia.

Materials and Methods

A case-control study was done on 50 thalassemic children compared with 50 normal children as controls, matched for age and sex, recruited from the outpatient department of CH&ICH Multan from January to September 2021. Thalassemic children were included who were diagnosed for more than 6 months, of 5 to 15 years of age, both genders and presented to the hematology outpatient department. For the control group, we enrolled the patients without Thalassemia visiting with minor illnesses (upper respiratory tract infection, gastroenteritis, urinary tract infection), to the general outpatient department of the hospital. The children of both groups were matched as closely as possible. The children who have known psychiatric disorders, any other chronic illness like tuberculosis (except complication of thalassemia), family history of any psychiatric disorder, and parental refusal were excluded.

Parents/guardians were detailed about the study and prior written consent was taken. The study was approved by the institutional ethical committee. No conflict of interest was involved in this study. Financial support was provided by the institution or pharmaceutical company.

A detailed history was taken from parents/guardians and patients. The patients were diagnosed with clinical presentation electrophoresis & considered significant if Hb F>50% and the diagnosis was made more than 6 months before enrolment. A complete examination was done on all patients. Anthropometric measurements were taken. The socioeconomic status and educational status of parents and children were noted. Families with monthly income<30,000rps were labeled low and >30,000rps as high socioeconomic status. One or both parents with completing their matric level were considered positive/significant educational status. Whether the patient is going to school or not is also inquired. Age of diagnosis of the disease and whether thalassemia is well controlled or not was also noted. The well-controlled disease was labeled if the blood transfusion requirement of the

patient was 1/month and serum ferritin level was below 1000 during the last 6 months period. Complications like diabetes mellitus, heart failure, skin discoloration, hemolytic facial features, and growth failure were diagnosed on clinical features, examination findings, and available investigations.

For psychosocial problems, a " Pediatric Symptom Checklist "was used. It "is a parent-report scale that has been standardized for detection of psychosocial impairment in general (cognitive, emotional and behavioral),⁸ established by Jellinek, et al as a screening tool for psychological and behavioral problems in children with fair validity and reliability. The checklist contains 35 items that are rated as "Never" "Sometimes" or "Often" scored "0" "1" and "2" respectively. We labeled "Never" if the symptom is not present ever. We labeled "sometimes" or "often" if symptoms occurred less than or more than 3 times in a week respectively. The total score is calculated by adding together the score for each of the 35 items. The children aged 6 through 16, a cutoff score of 28 or higher indicates psychological impairment. For children ages 4 and 5, the cutoff score is 24 or higher.

All information was recorded on the already designed Performa for final analysis. Data were analyzed by using SPSS version 22. The result was calculated in mean and standard deviation for quantitative data, frequencies, and percentages for qualitative data. The Chi-square test was used to calculate a probability value, which was considered statistically significant if less than or equal to 0.05. The prevalence ratio (ODDS ratio) with a 95%confidence interval of all variables was calculated.

Results

Out of 100 patients, 50 were cases and 50 were control (non-thalassemia). Males were predominant (74%) with male to female ratio of 1.2:1. Mostly children belonged to the age range between 5 to 10 years (60%) with a mean age of 9.2years (st dev. =2.9) in both groups There was no significance between both groups regarding age (p-value=0.083) (table-1).

Table-1 Baseline characteristics of children (N = 100)

VARIABLE	CASES(n=50)		CONTROL(n=50)		P-VALUE
	NO	%AGE	NO	%AGE	
Age (years) , mean ± SD		9.2years ± 2.9			
Age groups					
5-10years	30	60	39	78	0.083
>10to15years	20	40	11	22	
Sex					
Male	37	74	29	58	0.139
Female	13	26	21	42	
Socioeconomic status					
Low	41	82	41	82	1.00
High	9	18	9	18	
Education level of parents					
Educated	20	40	28	56	0.161
Non-educated	30	60	22	44	
Educational status of the patient					
School going	21	42	45	90	<0.001
Not school going	29	58	5	10	
Psychosocial impairment					
Yes	18	36	4	8	0.001
No	32	64	46	92	

40% of parents in the case and 52% in the control group were below matric. 42% and 90% of patients were going to school in case and control groups respectively. 82% of patients belonged to low, socioeconomically status in each group. (Table I). Psychosocial impairment was detected in 36% of cases and 8% of control respectively with a significant p-value (0.001).

Amongst the case group, thalassemia was diagnosed within 1st year of life in 74 % (n=37) patients, and 64 % (n=32) had well-controlled disease. Regarding complications, 20% (n=10) had Diabetes mellitus, 2% (n=1) heart failure, 74% (37) growth failure, 76% (n=38) hemolytic facial features, and 72% (n=36) skin discoloration. (Table-2)

Table-2 Characteristics about Thalassemia (N = 50)

	n,	%
Age of diagnosis		
Within 1 st year of life	37	74
After 1 st year of life	13	26
Management		
Well-controlled	32	64
Poor controlled	18	36
Complications		
Diabetes		
Yes	10	20
No	40	80
Heart failure		
Yes	1	2
No	49	98
Growth failure		
yes	37	74
No	13	26
Facial features		
Yes		
No	38	76
Skin discoloration		
Yes	12	24
No	36	72
	14	28

Relationship of different variables with psychosocial problems, Prevalence/odds ratio with a 95% confidence interval, and the p-value is shown in Table-3.

Table-3 Relation of variables with psychological problems, and p-value

Variable	Psychological problem		Odds ratio	95%confidence interval		P-value
	+ve	-ve		Lower	Upper	
Patients						
Case	18	32	0.560	0.154	2.03	0.001
Control	4	46				
Age groups						
5-10years	16	53	1.2	0.43	3.60	0.797
>10to15years	6	29				
Sex						
Male	18	48	2.8	0.868	0.942	0.125
Female	4	30				
Socioeconomic status						
Low			1.5	0.394	5.7	0.756
High	19	3				
	63	15				

Education level of parents						
Educated						
Non-educated	9	39	0.692	0.265	1.806	0.479
	13	39				
Education level of parents						
School going						
Not school going	11	53	0.418	0.159	1.10	0.081
	11	23				
Age of diagnosis						
Within 1 st year of life	12	5	0.560	0.154	2.033	0.504
After 1 st year of life	6	7				
Management						
Well controlled	7	25	0.178	0.050	0.631	0.013
Poor controlled	11	7				
Complications						
• Diabetes						
Yes	6	4	3.50	0.834	14	0.138
No	12	28				
• Heart failure						
Yes						
No	1	0				
• Growth failure						
Yes	17	32	0.944	0.844	1.056	0.360
No						
• Facial features						
Yes	18	19	1.68	1.26	2.24	0.002
No	0	13				
• Skin discoloration						
Yes	17	21	8.905	1.043	76.03	0.036
No	1	11				
	15	21	2.619	0.622	11.038	0.211
	3	11				

Discussion

Thalassemia has remained a socially noticeable stigma since the ages, because it is not easy to understand, in spite of improved education and increasing awareness. It is one of the conditions which affect the person with thalassemia and the whole family, this is not only because of the physical burden of thalassemia but also of cognitive and psychiatric problems. These psychosocial issues remain unidentified, resulting in poor mental health and adaptive functioning of the patient.

To our knowledge this is the first study on this topic, we assessed the psychosocial impairment in children with thalassemia by using a pediatric symptom questionnaire of 35 items. It was reported that

thalassaemic children experience more psychosocial problems including Cognitive, emotional, and behavioral problems as compared to non-thalassaemic children. These findings are similar to another study conducted in Egypt on thalassaemic children of almost the same age group by using PSC¹⁰. Some other researchers also found that thalassemia cases had more psychiatric and behavioral problems as compared to healthy children^{11,12,13}. The same results were concluded by a study carried out in the Dharmapuri district of Tamilnadu.¹⁴ The results of the study in Iran also indicated that there is significant depression, and anxiety in children with thalassemia compared with healthy subjects According to Behdani's results, children with thalassemia major have more psychological problems than healthy

ones.¹⁵Thalassemic children must be assessed for psychosocial illness, so that intervention can be started as early as possible.

The present study suggested that poorly controlled disease and complications like growth failure and heart failure are important factors for the occurrence of psychosocial issues in children with thalassemia, which is favored by other researchers too,^{10, 12} while growth failure has no relation with psychosocial problems described by another study.¹⁵ Raman also found that children not going to school are more prone to develop psychiatric illness, but it was non-significant in ours.¹² No significant difference is found regarding age and gender in relation to psychosocial problems in the current study which is similar results of another one,^{13,15} while Aydin described more psychosocial illness in females as compared to males.¹⁶ The limitation of my study was that this was conducted in a single center. No work has been done on this aspect of thalassemia at the national level, and limited data is available internationally, so we have limited studies to compare our data. The PSC is a tool to diagnose/screen overall psychosocial problems, it does not identify any specific condition like depression, anxiety, and conduct disorder, etc. Further psychological tools must be applied to diagnose a specific disorder.

Conclusion

Psychosocial problems like cognitive, emotional, and behavioral are common in children with thalassemia as compared to healthy ones, especially with poorly managed disease and complications. So, these patients must be referred for detailed psychological evaluation and management along with medical treatment.

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