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PSYCHOLOGICAL PROBLEMS ASSOCIATED WITH THALASSEMIA IN DIYALA PROVINCE, IRAQ

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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.

Objectives: Thalassemia is a chronic disease that manifests early in life that it leads to psychological and social problems for parents .We focused on parents to assess the impact of their child's disease and to assess the behavioral problems in multi-transfused thalassemic children and psychosocial factors affecting them.

Material and methods: This is a cross sectional study conducted in the Thalassemia Centre of Al-batool teaching hospital, Diyala, Iraq. The study was carried out from August 2013 to April 2014, parents who fulfilled the inclusion criteria were included in the study. The criteria were: a) established diagnosis of thalassemia of their child and the child was registered with the Thalassemia Centre for regular blood transfusion, b) parents who provided consent for the study

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.

KEYWORDS: BEHAVIORAL PROBLEMS. CHILD BEHAVIOR. CHECK LIST. MULTI-TRANSFUSED THALASSEMIA. FREQUENT HOSPITALIZATION. LONG-TERMCOSTLY CARE.

1. BACKGROUND

Thalassemia is a blood disorder passed down through families (inherited) in which the body makes an abnormal form of hemoglobin. This disorder results in excessive destruction of red blood cells, and there is no effective treatment. Patients require lifelong blood transfusion, usually started within 6 to 12months of birth of patient, which on other hand has its own complications. It is a chronic disease that manifests early in life that it leads to psychological and social problems for parents .We focused on parents to assess the impact of their child's disease.

Worldwide, thalassemia poses a serious public health problem due to the high prevalence. It extends from the Mediterranean basin and parts of Africa, throughout the Middle East, the Indian Sub-continent, South-East Asia, Melanesia and into the Pacific Islands, with reported rates ranging from 2% to 25% [1]. Each year, 50,000 to 100,000 children die of thalassemia major in low and middle income countries, while about 7% of the world's population is a carrier of a hemoglobin disorder [1]. The more severe forms are beta-thalassemia major, which warrants regular blood transfusion at an early age, and thalassemia intermedia which presents later and requires less frequent transfusions. The aim of regular blood transfusions is to eliminate the primary complications of severe thalassemia by ameliorating anemia and suppressing erythropoiesis. Patients are usually transfused at an early age. The chronicity and complications of thalassemia affect the quality of life of victims and parents and cause physical, psychological, and economic problems [2]. As there is no definitive cure for this disease, the majority exclusively depend on blood transfusions as a treatment option that creates a burden not only on health system but also on the affected families, who are vulnerable to, social, and psychological problems [3,4]. Various Quality of Life (QOL) studies conducted worldwide on thalassemia indicated poor indicators for the sufferers [5].

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.[6] 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.[7] They display psychosomatic symptoms and are frequently absent from school. Thalassemic children have more of negative self-concept when compared to their normal counterparts.[8]. Regular blood transfusions improve the overall survival of multi-transfused children but despite the progress made in preventing transfusion-transmitted infections TTIs) over the last few years, TTIs continue to be a problem in many parts of the world (9). Blood transfusion is the main risk factor for transmitting viral hepatitis, particularly in patients with hematological diseases (10).The TTI problem is directly proportional to the prevalence of infection in the blood donor community (11). Patients with thalassemia commonly receive transfusions and thus, are exposed to transfusion-associated infections .Among these infections, hepatitis B and hepatitis C are the most common (12). Hepatitis B is an important infection in patients with thalassemia and prevention by vaccination is necessary .Transfusional hemosiderosis is a frequent complication in patients with transfusion dependent chronic diseases such as thalassemia and severe type of sickle cell diseases. As there are no physiological mechanisms to excrete the iron contained in transfused red cells (1 unit of blood contains approximately 200 mg of iron) the excess of iron is stored in various organs. Cardiomyopathy is the most severe complication covering more than 70% of the causes of death of thalassemic patients. Although the current reference standard iron chelator deferoxamine (DFO) has been used clinically for over four decades, its effectiveness is limited by a demanding therapeutic regimen that leads to poor compliance. Despite poor compliance, because of the inconvenience of subcutaneous infusion, DFO improved considerably the survival and quality of life of patients with thalassemia. Deferiprone since 1998 and Deferasirox since 2005 were licensed for clinical use. The oral chelators have a better compliance because of oral use, a comparable efficacy to DFO in iron excretion and probably a better penetration to myocardial cells. Considerable increase in iron excretion was documented with combination therapy of DFO and Deferiprone. The proper use of the three chelators will improve the prevention and treatment of iron overload, it will reduce .[complications, and improve survival and quality of life of transfused patients. [13,14

2. MATERIALS AND METHODS

This is a cross sectional Study conducted in the Thalassemia Centre of Al-batool teaching hospital, Diyala, Iraq. The study was carried out from August 2013 to April 2014. All Parents who brought their children for blood transfusion

those parents who fulfilled the inclusion criteria were included in the study. The criteria were: a) established diagnosis of thalassemia of their child and the child was registered with the Thalassemia centre for regular blood transfusion, b) parents who provided consent for the study.Data was collected on a questionnaire comprising 25 questions that was self- designed to assess the psychological and social problems, (name, date of diagnosis, family history of thalassemia, family death, consanguinity, no(frequency) of transfusions, volume of transfusions, chelation type, chronic illness, no.of affected siblings, bone marrow aspiration, parents education, serum ferritin, liver function test, HBsAG and Anti HCV, hepatospelnomegaly, bone changes, social problems, financial problems, weight, height, OFC, school performance, behavioral problems, drug reaction).

3. RESULTS

There was a preponderance of males in parenteral treatment group and females in oral treatment group (Table 1) and overall there were 56 males haematologic among the 100 patients in the study. Apart from 5 individuals with b-thalassemia were not receive chelation therapy, all other patients had oral or parenteral chelation therapy . During the 9 months had taken 100 case as sample of thalassemic patients in Diyala city to assess the psychosocial problems and the results in (table 4) explain the social problems and behavioral problems more common in parenteral treatment while the school absence higher in oral chelation treatment group . In(table 1) the demographic data of the patients. Table 2 explain the comorbidity associated with both treatment group.

Table 1: Demographic data of the patients participating to the study.

XXXXXXXXXXXX	**Oral Chelation 27 case**	**Parenteral Chelation 68 case**	**P value**
Gender			
Male	13 (0.48%)	40 (58%)	
Female	14 (0.51%)	28 (41%)	
Parents Education			
NON	2 (0.07%)	10 (0.14%)	
Primary	12 (0.44%)	22 (0.32%)	
Secondary	7 (0.25%)	31 (0.45%)	
High education	6 (0.22%)	5 (0.07%)	
Physical activity			
Normal	13 (0.48%)	36 (0.52%)	
low	12 (0.26%)	32 (0.47%)	

Table 2: Co-morbidities associated with the disease in both modes of Chelation.

XXXXXXXXXXXX	**Oral Chelation** 27 case	**Parenteral Chelation** 68 case	**P value**
bone changes	12 (0.44%)	47 (0.69%)	
Liver	9 (0.33%)	16 (0.23%)	
Spleen	13 (0.48%)	57 (0.83%)	

Hepatitis(type B,C)	2 (0.07%)	6 (0.08%)	
Other chronic disease	2 (0.07%)	6 (0.08%)	
Bone aspiration	4 (0.14%)	10 (0.14%)	

Table 3: Disease characteristics

XXXXXXXXXXXX	**Oral Chelation 27 case**	**Parenteral Chelation 68 case**	**P value**
Age of onset, At or before 1st year After 1st year	20 (0.74%) 7 (0.25%)	50(0.73%) 18(0.26%)	
Frequency of transfusion, Monthly Less than month More than month	14 (0.51%) 11 (0.40%) 2 (0.07%)	39 (0.57%) 29 (0.42%) 1 (0.01%)	

Table 4

	Oral Chelation 27case	**Parenteral Chelation 68 case**	**P value**
Social problems	6 (0.22%)	27 (0.39%)	
School absence	19 (0.7%)	29 (0.42%)	
Financial problems	12 (0.44%)	30 (0.44%)	
Behavioral problems	12 (0.26%)	32 (0.47%)	

4. DISCUSSION

Studies over the past 25 years have shown that prevalence of behavioral disorders among thalassemic children ranged from 23 to 80%,[15-16] and these psychological disturbances adversely affect compliance to treatment in thalassemia.[17] 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[18] 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 [19].physical illnesses but had been neither recognized nor treated

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