



PSYCHOLOGICAL BURDEN ON CHILDREN WITH THALASSEMIA MAJOR AND THEIR PARENTS.

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ABSTRACT **Background And Objective:** Thalassemia is one of the prevalent hereditary diseases. children with thalassemia need care from the first years of their life owing to the physical and psychological effects of their disorder. Thalassemia is a concern not only for the children's health but also for the quality of life of both the children and their caregivers. This study investigated the relationship between the burden of care giving and the psychological conditions. **Materials And Methods:** In this analytical cross-sectional study, a total of 150 children with thalassemia major, transfusion dependent and 150 parents of thalassemia children were included. All participants completed questionnaires to assess their knowledge about thalassemia and their psychological symptoms. **Results:** 93(62%) children and 117 (78%) parents were found affected with psychiatric disorders. **Conclusion:** Thalassemia affects not only the persons with the disorder but also their caregivers in several aspects, including their psychosocial well-being. This study emphasises the role of a supportive group in the psychological well-being of caregivers, which could be used to prevent the pathological effects of caregiver burden and enhance their psychological well-being through counselling.

KEYWORDS : thalassemia, parents, psychiatric illness

Thalassemias are a group of genetic disorders caused by a mutation to the globin chains resulting in decreased haemoglobin (Hb) synthesis. Worldwide, the prevalence of thalassemia ranges from 0 to 19%, with highest rates in Southeast Asia, the Eastern Mediterranean (particularly Cyprus and Sardinia), and Sub-Saharan Africa. Beta-thalassemia major is a disorder characterized by the defective production of haemoglobin and excessive destruction of red blood cells. Haemoglobin comprises four protein subunits, that is, two α and two β . Genetic mutations in the gene encoding for the β subunits of the protein result in reduced or totally absent synthesis of the globin β - chains, leading to the formation of abnormal haemoglobin. This defect causes an abnormal development of red blood cells and ultimately anaemia, which is the characteristic symptom of thalassemia.

Thalassemia is a chronic disease that presents a range of serious clinical and psychological challenges. The effects of thalassemia on physical health can lead to physical deformity, growth retardation, and delayed puberty. Despite the critical advances in the knowledge of the psychological assessment in chronic patients, very few studies are carried out to investigate correlation between psychological conditions and quality of life in Thalassemia major (TM) patients.

Some of the previous studies showed that 80% of patients with thalassemia major have at least one psychiatric disorder. The most common psychiatric disorders reported among these patients or their family members included body dimorphic disorders (BDD), anxiety, depression, physical impairment, and the lack of control of anger. Also, these patients have numerous problems in their social and educational status. Although optional medical management has reduced the difficulties faced by Thalassaemic children and their families, still the psychosocial impact on the development of the sick children and family is a continuous process throughout life. Children with Thalassemia have to regularly attend hospital for blood transfusion and chelation therapy. Parents suffer from psychosocial burden because of expenses, stress and fear of death.

Aims And Objectives

To assess psychological burden in thalassemia major children and their parents.

MATERIAL AND METHODS

This is a cross sectional study conducted in the thalassemia day care centre of department of Paediatrics JK loan hospital, government Medical College kota.

Cases Were Divided Into 2 Groups

Group A consisted of 150 thalassemia major patients regularly attending daily day care centre for blood transfusion in JK loan hospital.

Group B consisted of 150 parents of thalassemia major children

coming regularly to the day care centre for transfusion in their children who were not having any major medical or surgical illnesses.

Sample size: 150 thalassemia major children and 150 parents of these children.

Inclusion Criteria

1. Thalassaemia major children between 5 to 16 years of age
2. Parents of thalassemia major children

Tools of the study

The selected thalassaemic major patients (group A) and their parents (group B) interviewed in detail using following tools for the purpose of meeting the above mentioned aims and objectives.

1. A specially designed proforma prepared for purpose of study.
2. Goldenberg's health questionnaire-12

RESULTS:

Table 1 Demographic Characteristics Of Children With Thalassemia Major

Variables	Frequency	Percentage %
Gender		
Male	82	54.6
Female	68	45.3
Religion		
Hindu	117	78
Muslim	33	22
Place		
City	70	46.6
Village	80	53.3
School grade		
None	12	8
Primary	78	52
Elementary	49	32.6
Secondary	11	7.3
Current schooling		
Yes	122	81.3
No	28	18.6
School dropouts		
With psychiatric disorders	65	69.89
Without psychiatric disorders	22	38.59
Family history of psychiatric disorders		
Yes	21	14
No	129	86

According to demographic characteristics 54.6 % children were male ,53.3% children belonged to village. Maximum children (52%) were studying in primary classes. 81.3 % children were attending schools

but 28% children were not going to school. School dropout rate was 69.89% in children having psychiatric disorders while it was 38.59% in children without psychiatric disorders.

In this study 93(62%) children and 117 (78%) parents were found affected with psychiatric disorders. Out of affected children ADHD, anxiety, depression, depression and anxiety both and phobic neurosis were the psychiatric disorders. Among above disorders depression was the most common psychiatric disorder.

Psychiatric Disorders In Children And Parents Of TM Children

Psychiatric disorder	Yes n(%)	No n(%)	Total n (%)
Children	93(62)	57(38)	150(100)
Parents	117(78)	33(22)	150(100)

Psychiatric Disorders Among Children

s.no.	Psychiatric disorder	N(%)
1	ADHD	06(04)
2	Anxiety	09(06)
3	Depression	39(26)
4	Depression and Anxiety both	21(14)
5	Phobic neurosis (social, needle)	18(12)
6	No psychiatric illness	57(38)
Total		150(100)

Out of 150 parents 117(78%) were suffering with psychiatric disorders. Dysthymia, generalised anxiety, depression and anxiety both, depression were the psychiatric disorders. Depression and anxiety both were the most common.

Psychiatric Disorders Among Parents

s.no.	Psychiatric disorders in parents	n (%)
1	Dysthymia	06(04)
2	Generalised anxiety	15(10)
3	Depression and anxiety both	75(50)
4	Depression	21(14)
5	No any psychiatric disorder	33(22)
6	Total	150(100)

DISCUSSION:

Psychosocial burden on children and adolescents with thalassemia affected many aspects of life such as education, time off school, sports, difference from friends/siblings, social interactions, family adjustment, anxiety, isolation, and depression.

Education was one of the greatest difficulties that affected children with thalassemia, as a result of frequent admissions to hospital for blood transfusions and medical treatment, which caused absence from school several times per month.

Results regarding psychiatric illness revealed that about 26% children experienced depression, which might be related to thalassemia symptoms and complications like a yellow face, short stature, delayed growth, inability to establish a family, and the possibility that their friends at school do not want to play with a sick child. These results indicate that thalassaemic patients need a supportive environment that helps to decrease their anxiety levels, to increase their social network and to decrease the effect of both negative behavioural and physiological reactions to isolation. Interesting finding in this study was that anxiety and depression were the most common psychopathological symptoms experienced by caregivers of patients with thalassemia. The caregivers were constantly worried about their children's physical health and future. Furthermore, they faced several financial burdens due to the prolonged treatment of thalassemia, which included regular transfusion of blood according to the severity of the disease and medicines to remove excess iron, constant care and fulfilment of the parental responsibilities. These factors may contribute and play a major role towards an increase in the prevalence of psychopathological symptoms of the caregivers and hinder them from achieving psychological well-being. In this study, it was found that the consequence of giving birth to children with major thalassemia was a challenge and life had changed for the majority of participants. Most of the challenges were related to caring for these children and the simultaneous emotional difficulties they experienced.

CONCLUSION:

The increased risk of psychosocial problems in thalassaemic patients indicates the need for continuous psychosocial support in order to reduce their emotional distress, to strengthen their coping competence

and to improve their quality of life. Nurses are in an important position to support children with thalassemia in the management of the disease, and to minimize the psychosocial burdens of the disease on parents and their children. The relationship between coping styles, seeking social support, and social interactions have implications for preventive intervention, and seeking social support may be effective in reducing the illness-related psychosocial burden. This study discovers the importance of caregiver's psychological well-being in determining the survival of children with thalassemia. This study will help the researcher to find effective thalassemia caregiver counselling methods to reduce psychological burdens that are still not widely published. Thus, new theories about guidelines for assessing the supportive care needs of caregivers of thalassemia children to design interventions through providing education and information that provides general and specific information, regarding facts about thalassemia, caregiving skills and symptoms management both when thalassemia is diagnosed, as well as during transfusion or treatment in hospital and when returning home and possibly other methods may be arrived at.

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