

## Observational Study

**Psychiatric disorders and caregiver burden in children with transfusion dependent  $\beta$ -thalassaemia and their caregivers**

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Children with thalassemia need care from the first years of life owing to the physical and psychological effects of their disorder. Thalassemia is a concern not only for the children's physical health but also the mental health of themselves and their caregivers.

**AIM**

To screen the psychosocial problems and assessment of psychiatric morbidities among thalassaemic children and their caretakers, along with an assessment of caregiver burden in them.

**METHODS**

In this observational cross-sectional study, children with transfusion-dependent thalassemia, were included and were assessed for psychiatric morbidity and global functioning. Their parents were assessed for psychiatric morbidity and the caregiver burden they faced. All the parents completed two different questionnaires to assess their knowledge about the psycho-social functioning [using Pediatric Symptom Checklist-35 (PSC-35)] of their children and the level of the burden faced by them by Caregiver Burden Scale (CBS).

**RESULTS**

A total of 46 children (28 boys and 18 girls) with transfusion-dependent thalassemia with a mean age of  $8.83 \pm 2.70$  years and 46 parents (12 fathers and 34 mothers) were included in this study. More than 32 children had some psychosocial problems on screening by PSC-35. On assessment by CBS moderate caregiver burden was perceived in domains of general strain, isolation, disappointment, emotional involvement, and environment. A total of 65.3% of

children and 62.7% of parents were diagnosed with psychiatric problems.

### CONCLUSION

Thalassemia affects not only the persons with the disorder but also their caregivers in several aspects, including their psychosocial well-being. This study emphasizes 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.

**Key Words:** Thalassemia; Children; Caregiver burden scale; Psychiatric morbidity

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**Core Tip:** Thalassemia is a major public health problem because of its high prevalence ranging from 2%-5%. Like other chronic illnesses, patients with thalassemia are vulnerable to emotional and behavioral problems making them susceptible to a myriad of psychiatric disorders. The emotional and psychological problems faced by thalassaemic children and their caregivers are often overlooked resulting in increased suffering and poor outcome. In this observational, cross-sectional study we analyze 46 children with transfusion-dependent Thalassemia for the presence of psychiatric disorders along with the caregiver burden experienced by the caregivers of these children.

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## INTRODUCTION

Thalassemia is a major public health problem because of its high prevalence ranging from 2%-5%, it extends from parts of Africa, the Mediterranean throughout the Middle East, Southeast Asia, and the Indian subcontinent[1-3]. Each year 50000-100000 children die of Thalassemia major in low- and middle-income countries[4]. The carrier rate for the beta thalassaemia gene varies from 1%-2% in Southern India to 3%-15% in Northern India. Children with thalassemia major present with pallor, failure to thrive, intercurrent infections, and hepatosplenomegaly, and they are generally diagnosed between 6 mo and 2 years of life. If undiagnosed and untreated, more than 90% do not survive beyond 3 to 4 years of age[5]. Similar to other chronic illnesses, patients with thalassemia are vulnerable to emotional and behavioral problems[6]. These children are susceptible to anxiety and depression due to fear of separation from family, restricted social activity, physical and facial deformities, fear of death, and limitations in school and outdoor activities. It has been observed that up to 80% of children with thalassaemia are likely to have psychological problems like anxiety disorder, depression, and oppositional defiant disorder[2]. Psychosocial burden is perceived even more in adolescents when they are confronted with various difficulties like identity formation and developing intimate relationships dealing with work. Their physical appearance and absence of sexual development is the major obstacle to social and personal life. Thalassemia also affects the caregivers' mental health, and family life as it causes lots of financial strain leads to ignorance of other children, and hampers occupational duties due to its long-term complications, and burdensome medical protocols[7-9]. There are many studies about psychiatric problems and the quality of life of patients with thalassemia[10]. Understanding of the psychiatric aspect of this disease is still in its infancy. Therefore, we planned this study to assess the occurrence of psychiatric disorders amongst children and their caregivers as well as to assess the caregiver burden in children of transfusion-dependent  $\beta$  thalassaemia major.

## MATERIALS AND METHODS

This observational, cross-sectional study was conducted in the department of Pediatrics of a tertiary care teaching institution in central India over a period of one year. Prior approval from the institutional ethics and research committee was obtained. Children with an established diagnosis of transfusion-dependant  $\beta$  thalassemia major in the age range of 5 to 16 years and their caregivers regularly attending the department for blood transfusion were chosen for the study. A sample size of 46 patients was

calculated to complete the objective of the study using the formula ( $n = 4pq/L^2$ ) where prevalence (p) was 3%, q = (100-p), and allowable error (L) was 5%. Written consent was taken from the parents/caregiver and assent was taken from children above seven years of age. Children, with other chronic disorders like epilepsy and comorbid neurological conditions like pre-existing mental retardation, developmental delay, and cerebral palsy and thalassaemic children less than five years and more than 16 years of age, were excluded. Relevant information including socio-demographic profile, age at diagnosis, details of chelation therapy, and blood transfusion was collected in a predesigned proforma. Socio-economic status was assessed using Modified Prasad's classification[11].

After recruitment, the complete physical and systemic examination was done by the paediatrician. The parents of the recruited children were given two questionnaires: Pediatric Symptom Checklist-35 (PSC-35) and Caregiver Burden Scale (CBS)[12]. PSC-35 is a parent-reported questionnaire designed to assess the psychosocial functioning of children in the domains of attention, externalizing, and internalizing symptoms. It has a sensitivity of 80% to 95% and specificity of 68% to 100% The PSC consists of 35 items that are rated as "never", "sometimes", or "often present" (scored 0, 1, and 2, respectively). The scores for all 35 items are summed up to calculate the total score. For children aged 6 through 16 years, the cut-off score is 28 or higher while the cut-off is 24 or higher for 4- and 5-year-old children. Children who scored above the cut-off were referred for Psychiatric assessment.

CBS had 22 questions about different aspects of caregivers' burden and it has factor analysis to yield results about 5 indices - general strain (8 questions), disappointment (5 questions), emotional involvement (3 questions), isolation (3 questions), and environment (3 questions)[13]. Scoring was done on a scale of 1-4 (not at all, seldom, sometimes, and often). The total burden index was the mean of all 22 items and the higher scores indicated a greater burden. The total burden of each domain was divided into three groups: Low burden (1.00-1.99), moderate burden (2.00-2.99), and high burden (3.00-4.00)[14]. All the children who met the cut-off score on PSC-35 were clinically interviewed by the Professor in psychiatry and were diagnosed using DSM-IV TR. All the parents, who perceived a higher burden of illness, were also interviewed by a psychiatrist and were diagnosed and managed accordingly. Quantitative variables were analyzed in terms of mean and SD. Qualitative data was depicted in numbers and percentages.

## RESULTS

A total of 46 children and their parents were included in this study, out of which 28 were males and 18 were females. Among parents 12 were fathers and 34 were mothers. The mean age of children was  $8.83 \pm 2.70$  years. Most of them were staying in Urban settings (63%). 58.69% of the population were belonging to nuclear families. Patients came from all the socio-economic strata of society but the lower class was dominant. Demographic details of the study population have been given in Table 1. The mean medical expense per month was  $11.89\% \pm 6.27\%$  of the total family income. In terms of caregiver burden, the caregivers have faced a moderate amount of burden in terms of general strain, isolation, disappointment, emotional involvement, and environment (Table 2). A total of 35 out of the 46 children scored above the cut-off score in assessment on PSC-35 and out of them, 30 children were diagnosed with various psychiatric disorders like major depressive disorder (15.2%), anxiety disorder (19.6%), attention deficit hyperactivity disorder (ADHD) (8.7%), elimination disorder (19.6%), panic disorder (2.2%) as shown in Table 3. Whereas in caregivers, 28.2% of caregivers suffer from depression, 4.3% from bipolar disorder, substance use disorder (10.9%), somatisation disorder (13.04 %), and 6.6% suffered from anxiety disorder (Table 3).

## DISCUSSION

Thalassemia is among the most common hemoglobinopathy in India. It has become a major health problem for patients and their families in many countries due to the cost of treatment which involves regular transfusions, iron chelation, medical follow-ups, and hospitalisations[15,16]. In recent years, attention is drawn to the evaluation of psychiatric disorders, and caregiver burden among patients and their caregivers[17,18]. Our study highlights the sociodemographic variables, caregiver burden, and psychiatric morbidities in children suffering from transfusion-dependent Thalassemia Major and their parents. In our study, the mean age of the children was  $8.83 \pm 2.70$  years with a male preponderance which is commonly seen in Indian settings[19]. However, studies done in the Middle East, Mediterranean, and west have shown the equal incidence of diseases in both sexes[20,21-24]. This male preponderance has been attributed to a gender bias, rather than an actual dominance of disease in the boys. Various studies across India have seen that a boy child is taken to a health facility more often than a girl child[25]. We further found that the majority of the caregiver (73.91 %) were females, this finding may be attributed to the Asian culture of parenting where mothers tend to stay at home and take care of their children. We have found, similarly, a significant impairment in the mental health of the caregivers of  $\beta$ -thalassaemic children, while their children undergo years of treatment, they often face isolation, strain,

**Table 1 Demographic details of the study population**

Variable	Male (28)	Female (18)	Total, n (%)
<b>Age (children)</b>			
4-8 years	10	9	19 (41.30)
9-12 years	12	5	17 (36.95)
13-16 years	6	4	10 (21.73)
<b>Age (parents)</b>			
< 20 years	2	5	7 (15.2)
21-30	6	18	24 (52.17)
31-40	3	9	12 (26)
> 40	1	2	3 (6.5)
<b>Residence</b>			
Rural	15	2	17 (37)
Urban	13	16	29 (63)
<b>Family type</b>			
Nuclear	17	10	27 (58.69)
Joint	11	8	19 (41.30)
<b>Socioeconomic status (prasad's scale)</b>			
Upper middle class	3	4	7 (15.21)
Middle class	7	3	10 (21.7)
Lower middle class	6	5	11 (23.91)
Lower class	12	6	18 (39.13)

**Table 2 Caregiver burden in the parents of thalassaemic children**

Items	Mean
General strain	2.77
Isolation	2.93
Disappointment	2.77
Emotional involvement	2.78
Environment	2.75

and disappointment. Most of them suffer from moderate caregiver burden. As mothers are emotionally more vulnerable and they undertake the caregiver role in our society we found a higher ratio of burden in females caregiver, our finding is by a study done by Sinno *et al*[26] and a study done in Iranian mothers of thalassaemic children where they also observed high caregiver burden and strain[27].

Children and families suffering from any chronic illness have a significant impact on their mental health. Parents' anxiety about their child's illness may lead to restrictions on many normal activities of childhood and can prevent the overall development of the child. These things in the long run can make a child prone to many psychiatric disorders. Along with children even parents of these children faces isolation, and emotional and financial burden in their life, over time the parents' attitude may result in over-protective behaviour or open rejection. The child's feelings and reaction to his illness may affect his relationships with his siblings, peers, and his parents[28]. Studies done in the past 25 years have shown that the prevalence of Psychiatric disorders in thalassaemic children ranged from 23 to 80%, and these problems affect treatment compliance[29]. In the present study, 65.3% of the thalassaemic children had a psychiatric problem and Among caregivers, 62.67% had psychiatric problems which is in accordance with the results of the previous studies[4,5,13]. Depression which is associated with medical illness is one of the important subgroups of mood disorders. The increased prevalence of depression has been associated with chronic medical diseases, and the prevalence of depression increases with co-occurring medical conditions[13]. We found that 15.2% of children suffered from Major Depressive disorder

**Table 3 Psychiatric diagnosis among thalassaemic children and caregiver, n (%)**

Psychiatric Disorder	Children	Caregiver
Major depressive disorder	7 (15.2)	13 (28.2)
Bipolar I disorder	0 (0.0)	2(4.3)
Generalized anxiety disorder	9 (19.6)	2 (4.3)
ADHD	4 (8.7)	0 (0.0)
Elimination disorder	9 (19.6)	0 (0.0)
Panic attack	1 (2.2)	1 (2.2)
Substance use disorder	0 (0.0)	5 (10.9)
Somatization disorder	0 (0.0)	6 (13.04)
Total	30 (65.3)	29 (62.67)

ADHD: Attention deficit hyperactivity disorder.

earlier studies have noted a similar trend. In our study, we found that 28.2% of parents of children with Beta Thalassemia Major suffered from a major depressive disorder. In a previous study, UL Haq *et al*[30] found that most of the caregivers suffered from mild depression which is similar to our finding. In a study done for the evaluation of depression in mothers of patients with thalassemia or hematological malignancies, Shargi *et al*[31] reported the frequency of depression as 51%.

In the present study, 19% of patients were found to have nocturnal enuresis. In an earlier study, Beratis found that 12 % of their sample of pre-adolescent children with Thalassemia had nocturnal enuresis. Aydin *et al*[7] reported the prevalence of nocturnal enuresis to be 8% of children with TM. As we have not investigated the renal function in our study, it will not be possible to comment on the etiological factor of nephropathy. The impact of nocturnal enuresis extends to the caregiver as well adding up their miseries, as they have to wake up every night or change and wash their beddings. Generalized anxiety disorder, was seen in more than 19% of children followed by ADHD and panic attacks. Not many studies have assessed the long-term effect of chronic anaemia on the attention and hyperactivity of children, but some studies should be encouraged to study these aspects of long-term illness[31]. A significant number of parents suffered from somatization disorder (13.04%), generalized anxiety disorder, and bipolar disorder. This high percentage of somatisation disorder indicates the caregivers' fragile mental state as they are using neurotic defenses to deal with the struggle of life. We found that substance use disorder was seen in 10.9% of parents, it can be assumed that keeping aside the genetic susceptibility we may attribute substance use to cope with problems and hardships which accompany the lives of these parents. Studies done in Bangalore reported a high prevalence of psychiatric problems in caregivers of thalassaemic children which includes substance use disorder and depression[29]. Our study was limited by the small sample size. Also, it was a hospital-based study so the results cannot be generalized.

## CONCLUSION

Our study showed that the parents of children with transfusion-dependent thalassemia major suffer from high caregiver burden and many of them also suffered from dysthymic disorder, somatoform disorder, and substance addictions. These children also suffered from various psychiatric problems like generalized anxiety disorder, elimination disorder, dysthymic disorder, and other psychiatric ailments. Due to their chronic condition and associated psychiatric morbidity, they have slight impairment in global functioning. Our study highlights the importance of comprehensive care and appropriate psychiatric intervention for thalassaemic children and their caregivers.

## ARTICLE HIGHLIGHTS

### Research background

Thalassemia is highly prevalent in Indian Subcontinent with prevalence rates varying from 2%–5%. These children and their caregivers experience multiple emotional and psychological problems stemming from the poor physical health of the child and resultant recurrent hospitalisations.

### **Research motivation**

Psychiatric co-morbidities in these children and their caregivers have remained unexplored resulting in high emotional and psychological suffering. Assessing the same would result in the recognition of high psychiatric co-morbidities faced by this subset leading to the holistic care of these patients.

### **Research objectives**

Current study aimed to screen the psychosocial problems and assessment of psychiatric morbidities among thalassaemic children and their caretakers, along with an assessment of caregiver burden in them. The objectives of the study were all met implicating the high prevalence of psychiatric co-morbidities faced by these patients.

### **Research methods**

In this observational cross-sectional study, children with transfusion-dependent thalassemia were included and were assessed for psychiatric morbidity and global functioning. Their parents were assessed for the psychiatric morbidity and caregiver burden faced by them. All the parents completed two different questionnaires to assess their knowledge about the psycho-social functioning [using Pediatric Symptom Checklist-35 (PSC-35)] of their children and the level of the burden faced by them by Caregiver Burden Scale (CBS).

### **Research results**

A total of 46 children (28 boys and 18 girls) with transfusion-dependent thalassemia with a mean age of  $8.83 \pm 2.70$  years and 46 parents (12 fathers and 34 mothers) were included in this study. More than 32 children had some psychosocial problems on screening by PSC-35. On assessment by CBS moderate caregiver burden was perceived in domains of general strain, isolation, disappointment, emotional involvement, and environment. A total of 65.3% of children and 62.7% of parents were diagnosed with psychiatric problems.

### **Research conclusions**

The study implicated a high burden of psychiatric disorders like generalized anxiety disorder, elimination disorder, and dysthymic disorder among children. The caregivers were also revealed to be suffering from an entire spectrum of psychiatric disorders ranging from dysthymic disorders to substance addictions.

### **Research perspectives**

More such research should be conducted with a larger sample size to better gauge the extent of psychiatric co-morbidities among these patients. There is a need to bring about a paradigm shift in the healthcare protocols to ensure holistic care of these patients and their caregivers.

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## **FOOTNOTES**

**Author contributions:** Sahu S participated in the data collection, and interpretation of data and executed the study; Tonk S participated in the data collection, and interpretation of data; Agrawal A participated in the data analysis and manuscript writing; Srivastava J participated in drafting and editing the final manuscript.

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