

PROSPECTIVE CASE CONTROL STUDY ON PREVALENCE OF ANXIETY DISORDERS IN CHRONICALLY TRANSFUSED THALASSEMIA PATIENTS OF AGE GROUP 8-18 YEARS AND THEIR PARENTS

Dr. Isha Narula¹, Dr. Sandeep Aggarwal², Dr. Manmeet Kaur Sodhi³, Dr. Shallu Aggarwal⁴

¹Post graduate student (DCH) Government Medical College Amritsar, Punjab India

²Assistant Professor Pediatrics at Government Medical College Amritsar, Punjab India

³Professor Pediatrics Government Medical College Amritsar, Punjab India

⁴Head of Department Eye District Hospital Amritsar, Punjab India

Corresponding author: Dr. Sandeep Aggarwal, Assistant Professor Pediatrics, Government Medical College Amritsar, Punjab India

ABSTRACT

Aim: done to assess the anxiety levels and in chronically transfused thalassemia patients of age group 8-18 years and their parents. **Methodology :** 100 cases of thalassemia of age group 8-18 years who were on regular blood transfusion and 100 age and sex matched cases not suffering from thalassemia or other chronic disorder were included from the OPD or ward formed the control group. Demographic profile and clinical data will be recorded for both the cases and controls using the same written semi structured pretested proformas. Anxiety level among the participants, was evaluated using pre-validated Hamilton Anxiety Score (HAM-A Score).

Results : we observed that parents of children suffering from thalassemia had anxiety prevalence of 38% in which 18% had mild, 11% had moderate and 9% had severe. Parents of control group of adolescents had anxiety prevalence of 26% with 12% having mild, 9% moderate and 5% severe. Among adolescent children suffering from thalassemia 26%, showed anxiety, in which 17% had mild, 6% moderate and 3% had severe as compared to 18% prevalence in the control group with 10% mild, 5% moderate and 3% severe. The prevalence of anxiety among the cases as per the gap in blood transfusion. It was observed that anxiety was significantly more in elderly patients and who had less gap in between transfusion. **Conclusion :** The patients with thalassemia are at risk of developing anxiety disorders more than the normal adolescents. Thalassemia patients require life long psychological support for prevention mental health issues. Mood disorders of children and adolescents are likely to continue in adulthood. Parents of thalassemia children are also at high risk of developing anxiety disorders, this affects the family functioning. Identification, assessment and treatment at earliest stages are warranted for achievement of better prognosis at adulthood.

INTRODUCTION

The world thalassemia has been derived from Thalassa which in greek means sea and Haema which means blood.¹Thalassemia is a serious public health problem throughout the Mediterranean, middle east and south east Asian region.²Thalassemia is an autosomal recessive hemolytic anemia that results from defective production of hemoglobin. It is of two types alpha and beta thalassemia, the later being more common. Beta thalassemia major is a chronic disorder of blood having a disruptive impact on life. The patient presents with hemolytic anemia, growth retardation, hepatosplenomegaly and skeletal abnormalities³.

Worldwide approximately 3% of population carries alleles for beta thalassemia.⁴In India every year 10000 children are being born with thalassemia which approximately accounts for 10% of the total world incidence of thalassemia affected children and one in eight of thalassemia carriers live in India. In India there are nearly 42 million carriers of beta thalassemia trait. There are communities in which it is more prevalent like sindhis, Punjabis, gujaratis, Bengalis.^{1,4}

The management of thalassemia is lifelong and includes repeated blood transfusion and chelation. The affected children suffer from negative self concept and low self esteem when compared to healthy

children.⁵It is expected that thalassemia children are at high risk of developing behavioral and psychosocial problems such as opposition, passiveness, anxiety, phobias and depression. This in turn affect their self confidence and also leads to negative thoughts which not only affects their quality of life but also compliance to therapy.⁵

The Hamilton Anxiety Rating Scale (HAM-A) is a psychological questionnaire used by clinicians to rate the severity of a patient's anxiety.⁶ Allaying the stress and anxiety from the lives of children will surely improve the quality of life of thalassemic patients thereby increasing their school attendance and academic performance. This will ensure that such children can hold jobs, improving their financial stability, leading to better quality of medical care⁷.

Hence this study will be done to assess the anxiety levels and in thalassemic children and their parents, so that along with physical well being, the mental and social well being of thalassemia children and adolescents is improved.

MATERIALS AND METHODOLOGY

The present prospective case control study was conducted at the Department of Pediatrics, Government Medical College, Amritsar after approval from the institutional ethical committee. Written informed consent was taken by all the participants before enrolling them in the study.

The study consisted of 100 cases of thalassemia of age group 8-18 years who were registered in the Department of Pediatrics, Government Medical College, Amritsar. Children who were on regular blood transfusion, able to communicate verbally were included in the study. Children and adolescents with other chronic comorbidities like DM, Hypertension, Cardiovascular diseases, Renal diseases, lung diseases, neurovascular diseases, previously diagnosed psychiatric illnesses hypothyroidism and having HIV were excluded from the study.

100 age and sex matched cases not suffering from thalassemia or other chronic disorder were included from the OPD or ward formed the control group.

Demographic profile and clinical data will be recorded for both the cases and controls using the same written semi structured pretested proformas. Anxiety level among the participants, was evaluated using pre-validated Hamilton Anxiety Score (HAM-A Score).

The HAM-A probes 14 parameters and score the results. Each item is scored on a 5-point scale, ranging from 0=not present to 4=severe, with a total score range of 0–56, where <17 indicates mild severity, 17-24 indicates moderate severity and 25-30 indicates moderate to severe stress.

RESULTS ANALYSIS

The cases of thalassemia children were divided into three groups according to interval of blood transfusion and two groups according to age group.(Table 1 and 2)

The results of the study showed that parents of children suffering from thalassemia had anxiety prevalence of 38% in which 18% had mild, 11% had moderate and 9% had severe. Parents of control group of adolescents had anxiety prevalence of 26% with 12% having mild, 9% moderate and 5% severe(Figure 1).

Among adolescent children suffering from thalassemia 26%, showed anxiety, in which 17% had mild, 6% moderate and 3% had severe as compared to 18% prevalence in the control group with 10% mild, 5% moderate and 3% severe(Figure 2). Table 3 shows the prevalence of anxiety among the cases as per the gap in blood transfusion. It was observed that anxiety was significantly more in patients who had less gap in between transfusion ($p=0.006$). Also on comparing the age group and prevalence of anxiety (Table 4) it was observed that anxiety was significantly more in elderly patients($p=0.001$)

Table 1: Distribution of cases according to duration of transfusion

Duration of transfusion	No. of cases
10-15 days	50
15-30 days	34
>30 days	16

Table 2: Distribution of cases according to age group

Age group	No. of cases
8-12 years	63
12-18 years	37

Figure 1: Comparison of anxiety between parents of control and cases.

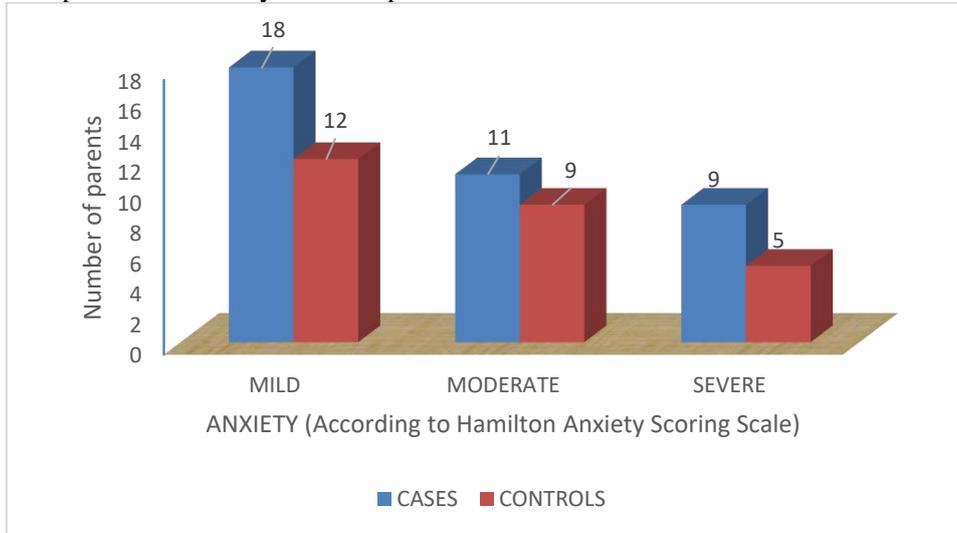


Figure 2: Comparison of anxiety between adolescence in control and cases.

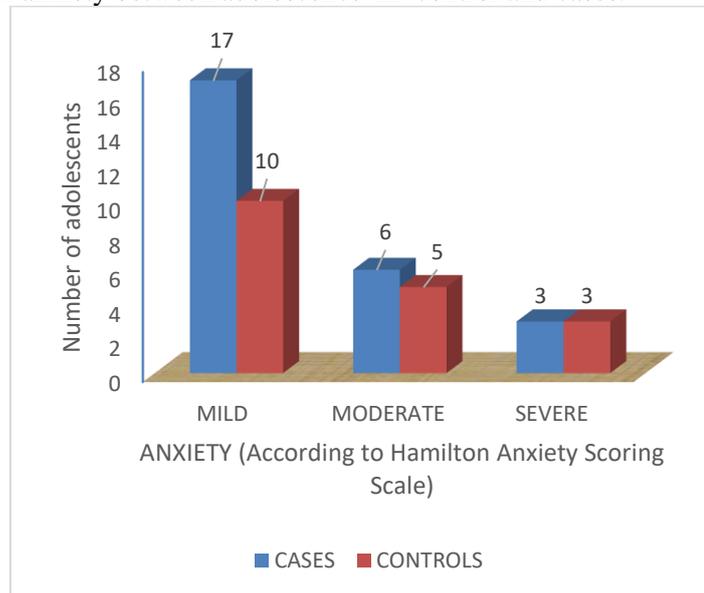


Table 3: Prevalence of anxiety among cases with regard to blood transfusion gap

Blood transfusion gap	Anxiety			
	Yes		No	
	No.	%age	No.	%age
10-15 days	20	76.92	30	40.54
15-30 days	4	15.38	30	40.54
>30 days	2	7.69	14	18.92
P-value: 0.006*				

*p<0.05; Significant and **p<0.001; Highly Significant

Table 4: Prevalence of anxiety among cases with regard to age group

Age group	Anxiety			
	Yes		No	
	No.	%age	No.	%age
8-12 years	9	34.62	54	72.97
12-18 years	17	65.38	20	27.03
P-value: 0.001*				

* $p < 0.05$; Significant and ** $p < 0.001$; Highly Significant

DISCUSSION:

Beta thalassemia major is a homozygous state which causes hemolytic anemia demanding regular blood transfusions. The availability of safe blood transfusion with adjuvant chelation therapy has facilitated and extended the survival rates to these patients. Different studies have shown psychological disorders are more common in thalassemia patients. Environmental and social factors especially family play important role in improving and decreasing anxiety of these patients. HAM A scores include the following for scoring the severity. An anxious mood, tension, fears, insomnia, intellectual, depressed mood, somatic symptoms, cardiovascular symptoms, respiratory symptoms, gastrointestinal symptoms and autonomic symptoms. The scale is from 0-4 for each parameter⁸.

HAM A severity was graded based on total score as mild (<17), moderate (18-24) and severe (25-30) anxiety. This study shows 38% prevalence of anxiety in parents of thalassemia cases as compared to 26% in the control group. The thalassemia cases showed 26% prevalence of anxiety in adolescents as compared to 18% in the control group. In a study done by Hashemi et al⁹, anxiety was seen in 41.2% as compared to 26% in our study. In a study done by JitendraMugali et al¹⁰ anxiety was seen in 38.71% as compared to 26% in our study.

Parents of children with thalassemia and adolescents with the disease usually suffers from psychosocial and behavioral problems. Sandra et al. found that the majority of the caregivers in their study (77.3 percent) experienced moderate stress and 21% had mild stress¹¹. Pruthiet al¹² conducted a study in Delhi and discovered that 57 percent of caregivers had psychiatric issues, including depressive illnesses. Another study conducted by Aziz et al¹³ in Pakistan indicated that 29% of parents had moderate to severe depression and 3% had severe depression as a result of their children's thalassemia.

Parents of thalassemic children are concerned not just about their children's goals, expectations, and quality of life, but also about the influence of diagnosis and treatment on family stability and dynamics. The appearance of their child, bone deformities, short stature, poor self-image, frequent hospital visits for transfusions, delayed or absent sexual development, impaired fertility, and other disease-related complications such as heart disease, bone disease, diabetes, infections, and others are among the concerns of parents.¹⁴Marked development in the diagnosis and management has not been matched by progress in psychosocial rehabilitation of thalassemia patients. On parents perspective it is a frightening and worrisome experience in which they have to cope up with the psychological aspects of Thalassemia along with their regular visits to the Thalassemic centers for blood tests and blood transfusion with iron chelation therapy and their determination to fulfill the treatment. The consequence of Thalassemia is extremely stressful and patients' face a variety of physical, psychological and social problems. Considering these experiences, in India Thalassemia might be officially considered as a disability, requiring a multiple theoretical as well as a prolonged intervention method to tackle it.⁶The increase risk of psychosocial and behavioral problems in Thalassemics and their parents indicated the importance of a lifelong psychosocial support for the prevention of mental health issues. The patients and parents who were more conscious of the illness were more worried but more compliant with the therapy and needed.^{15,16}

In present study it was observed that stress was significantly more in elderly patients and in patients in whom the gap in the transfusion was less. Zolay et al¹⁷ in their study found no significant difference in the anxiety levels with respect to age and frequency of transfusion which was in contrast to the present study. There have been very limited studies that study the effect of age and transfusion frequency on the anxiety levels. Our results could be attributed to the fact that as the child with thalassemia grows, the problems associated with the disease also increases. Common problems

are the chronicity of thalassemia major disease, the need for blood transfusion at regular intervals throughout life, body image disorders, being evaluated differently from peers due to the delay in growth and development, high treatment costs, difficulties in recruitment, the need for regular leave to continue treatment throughout their working life and education. All of this requires a constant effort to overcome serious health problems throughout the life of patients with thalassemia major. Therefore, psychosocial problems may be the most important problems for these patients (16,17).

CONCLUSION:

The patients with thalassemia are at risk of developing anxiety disorders more than the normal adolescents. Thalassemia patients require life long psychological support for prevention mental health issues. Mood disorders of children and adolescents are likely to continue in adulthood. Parents of thalassemia children are also at high risk of developing anxiety disorders, this affects the family functioning. Identification, assessment and treatment at earliest stages are warranted for achievement of better prognosis at adulthood. Regular screening for symptoms is essential to identify at risk individual, so as to provide appropriate psychological support with ultimate goal to improve both emotional and physical health.

REFERENCES

- 1) Galanello R, Origa R. Beta-thalassemia. *Orphanet J Rare Dis.* 2010 May 21;5:11. doi: 10.1186/1750-1172-5-11. PMID: 20492708; PMCID: PMC2893117.1
- 2) Flint J, Harding RM, Boyce AJ, Clegg JB. The population genetics of the hemoglobinopathies. *Bailliere's Clinical Hematology.* 1998;11:1–50.
- 3) Bajwa H, Basit H. Thalassemia. [Updated 2021 Nov 5]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2022 Jan-. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK545151/>
- 4) Thiyagarajan A, Bhattacharya S, Sharma N, Srivastava A, Dhar DK. Need for a universal thalassemia screening programme in India? A public health perspective. *J Family Med Prim Care.* 2019 May;8(5):1528-1532. doi: 10.4103/jfmpc.jfmpc_90_19. PMID: 31198708; PMCID: PMC6559078.
- 5) Tarım HŞ, Öz F. Thalassemia Major and Associated Psychosocial Problems: A Narrative Review. *Iran J Public Health.* 2022 Jan;51(1):12-18. doi: 10.18502/ijph.v51i1.8287. PMID: 35223621; PMCID: PMC8837879.
- 6) Hamilton M. The assessment of anxiety states by rating. *Br J Med Psychol* 1959; 32:50–55.
- 7) Vaccarino AL, Evans KR, Sills TL, Kalali AH. Symptoms of anxiety in depression: assessment of item performance of the Hamilton Anxiety Rating Scale in patients with depression. *Depress Anxiety.* 2008;25(12):1006-13.
- 8) Bech P. Fifty years with the Hamilton scales for anxiety and depression. A tribute to Max Hamilton. *PsychotherPsychosom.* 2009;78(4):202-11.
- 9) Hashemi AS, Banaei-Boroujeni S, Kokab N. Prevalence of major depressive and anxiety disorders in hemophilic and major beta thalassaemic patients. *Iranian Journal of Pediatric Hematology and Oncology.* 2012 Mar 10;2(1):11-6.
- 10) Mugali J, Pattanshetty M, Patansetti N. Study of anxiety among thalassemia major adolescent patients. *Int J Ind Psychol.* 2017;4(2):86.
- 11) Sandra J, Saldanha. Stress and Coping among Parents of Children Having Thalassemia. *International Journal of Science and Research (IJSR),* July 2015; 4(7): 2319-7064.
- 12) Pruthi G. K. and Singh T. B. Psychosocial Burden and Quality of life in parents of Children with Thalassemia and Cerebral Palsy: A Comparative study. *Delhi psychologist,* 2010; 2(1): 46-57 19.
- 13) Kashif Aziz, Breera Sadaf & Sadiya Kanwal. Psychosocial problems of Pakistani parents of Thalassaemic children: a cross sectional study done in Bahawalpur, Pakistan. *BioPsychoSocial Medicine,* 2012, 6:15
- 14) Shalrigram D, Girimaji SC, Chaturvedi SK. Psychological problems and quality of life in children with thalassemia. *Indian Journal Pediatrics,* 2007; 74

- 15) Ali S, Sabih F, Jehan S, Anwar M, Javed S. Psychological distress and coping strategies among parents of beta-thalassemia major patients. In International Conference on Clean and Green Energy 2012 (Vol. 27, No. 2012, pp. 124-8).
- 16) Roy T, Chatterjee SC. The experiences of adolescents with thalassemia in West Bengal, India. Qual Health Res. 2007 Jan;17(1):85-93.
- 17) Zolaly MA, Zolaly FM, Al Belawi L, Shuqdar R, Al Belawi MA Sr, Alwasaidi TA, Albadrani M. Depression, Anxiety, and Stress Symptoms in Patients With Beta Thalassemia Major in Almadinah Almunawwarah, Saudi Arabia. Cureus. 2020 Nov 7;12(11):e11367.
- 18) Elzaree F, Shehata M, Wakell M, et al (2018). Adaptive functioning and psychosocial problems in children with beta thalassemia major. Open Access Maced J Med Sci, 6 (12): 2337-2341. 17.
- 19) Vosper J, Evangeli M, Porter JB, et al (2018). Psychological factors associated with episodic chelation adherence in Thalassemia. Hemoglobin, 42 (1): 30-36.