

Psychosocial problems in thalassemic adolescents and young adults

Abstract

Background: With the availability of better treatment regimen, life span of thalassemic patients is increasing. Chronic nature of thalassemia and its intensive and demanding treatment result in significant psychological burden on the patients and their families. A lot has been studied about beta-thalassemia major but little attention has been paid to the psychological aspect of this disease. Hence, the study was planned to analyse the psychosocial problems in thalassemic adolescents and young adults. **Materials and Methods:** This was a cross-sectional study, conducted from January 2007 to March 2008 in thalassemic day-care centre of a tertiary care teaching hospital. Fifty four thalassemic children and controls above 9 years of age were enrolled. Psychosocial assessment done with assessment of Finer Psychopathology using ICMR Symptom checklist (ICMR task force, 1983). The prevalence of various problems was calculated and compared with controls. Student's *t*-test and Chi-square test were used for testing differences in variables. **Results:** Patients were divided into three groups – Group A (10-15 years, 30 patients); Group B (15-20 years, 18 patients), and Group C (20-25 years, 6 patients). In group A, behavior problems were common (12 patients –40%) ($P<0.001$, significant). In group B, mood disorders were common (8 patients, 44%) ($P<0.001$, significant). In group C, psychotic symptoms were common (3 patients, 50%) ($P<0.05$, significant). **Conclusion:** Our findings support the hypothesis that psychosocial problems are more in thalassemic adolescents and young adults. Psychosocial aspects need to be addressed in the overall treatment of children with thalassemia.

Key words:

Adolescent, affective symptoms, depression, mood disorder, psychology, psychosocial problems, thalassemia

Introduction

Beta thalassemia is the most common form of hemolytic anemia,^[1] and every year approximately 60,000 thalassaemic babies are born worldwide.^[2] With the availability of better transfusion regimen, iron chelation therapy, proper management of complications, and good supportive care, it is now possible for a thalassemic patient to have a near normal life span. A lot has been studied about beta-thalassemia major but little attention has been paid to the psychological aspect of this disease. Chronic nature of thalassemia and its intensive and demanding treatment result in significant psychologic burden on the patients

and their families. Social isolation, reduced self esteem, lower academic achievement, and stigmatization, all lead to psychological burden.^[3,4] Patient with thalassemia major need additional psychological support to reduce emotional stress, to strengthen competence, and for better compliance to therapy in daily life. Thus, the study was planned to analyse the psychosocial problems in thalassemia adolescents and young adults and hypothesised that psychosocial problems are more in thalassemic adolescents and young adults.

Materials and Methods

This was a cross-sectional study conducted between January 2007 to March 2008, in thalassemia day care centre in

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a tertiary care teaching hospital (Choithram Hospital and Research Centre, Indore) and enrolled 54 patients. Children of both sexes of age more than 9 years, having both parents alive and living together, negative for human immunodeficiency virus and no family history of any chronic illness or psychological illness, and attending the thalassemia day care centre were enrolled. Patients were diagnosed by high performance liquid chromatography (HPLC). Control group consisted of 54 children of matched age group and social background. Psychosocial assessment done with Finer Psychopathology using ICMR Symptom checklist (ICMR task force, 1983). A detailed, structured interview was conducted for each patient and psychologist helped them for completing the checklist. Student's *t*-test and Chi-square test were used for testing differences in variable.

Results

Out of 54 patients, 43 were males (79.62%) and 11 were females (20.37%). Patients were divided in three groups group A (10-15 years, 30 patients), group B (15-20 years, 18 patients), and group C (20 to 25 years, 6 patients). Different types of psychosocial problems were observed in different age groups [Table 1]. In group A, behavior problems (nervousness, aggression, temper tantrums, and overactive) were common and found in 12 patients (40%). When compared to other groups and controls, difference was statistically significant ($P < 0.001$). Other common problems were school problems (30 patients, 100%) and mood disorder (5 patients, 18%). In group B, mood disorders (unduly depression, loneliness, panic, free floating anxiety, worrying) were common and found in eight patients (44%). When compared to other groups and controls, difference was statistically significant ($P < 0.001$). Other problems were school problems (18 patients, 100%); sleep disturbances (5 patients, 27%), and situation

specific anxiety (4 patients, 22%). In group C, psychotic symptoms (delusion, hallucination, thought disorder, lack of insight) were found in three patients (50%) and was statistically significant ($P < 0.05$, significant). Other common problems were school problem (6 patients, 100%) and sexual problem (decreased libido, fear of impotence, decrease interest in opposite sex) (2 patients, 33%). Suicidal attempt was observed in 1 patient.

Discussion

Beta thalassemia major is a chronic, genetically determined hematological disorder and has gained little investigation on the psychological aspects of the disease and psychological adjustment of patients with this disease. Adolescence itself is a time which demands more adjustment skills. An illness superimposed on the existing problems causes an emotional outburst, which needs to be handled properly. If not, the overlooked needs may become manifest as psychological problems. A recent study suggests that anxiety disorders may be more strongly related to early stress exposure.^[5] Similar to reported data,^[6] school problems were common and found in all thalassemic patients because of frequent hospitalization, school absenteeism, and poor peer group adjustment and disease related complications. In the age group of 10-15 years, it was found that patients were not concerned about the disease and its effects in future. These patients were overactive, aggressive, and had temper tantrums. Similar to recent study,^[7] behavior disorders were common in this age group. Patients from the age group of 15 to 20 years were more concerned about life, disease related side effect and life expectancy. Similar to reported data,^[8,9] there was significant free-floating anxiety, depression, nervousness, and fear of death in this age group. Psychotic problems and sexual problems were common in age group of 20-25 years. Similar to reported data,^[8] rate

Table 1: Frequency of symptom group on symptom check list

| Symptoms group | Group A | | Group B | | Group C | |
|---------------------------------|----------|-------------|----------|-------------|----------|-------------|
| | Case (%) | Control (%) | Case (%) | Control (%) | Case (%) | Control (%) |
| Speech and language difficulty | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 0 (0) |
| Reading difficulty | 2 (6) | 1 (5) | 2 (11) | 1 (5) | 1 (16) | 1 (16) |
| Sleep disturbance | 8 (26) | 4 (13) | 5 (27) | 2 (11) | 1 (16) | 1 (16) |
| Appetite and eating disturbance | 6 (20) | 4 (13) | 2 (12) | 2 (11) | 1 (16) | 1 (16) |
| Disturbance of elimination | 4 (12) | 3 (10) | 0 (0) | 1 (5) | 1 (16) | 0 (0) |
| Behavior disorder | 12 (40) | 2 (6) | 4 (22) | 1 (5) | 1 (16) | 0 (0) |
| Mood disorder | 5 (18) | 2 (6) | 8 (44) | 1 (5) | 1 (16) | 0 (0) |
| Suicidal ideation and attempt | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 1 (16) | 0 (0) |
| Situation specific anxiety | 6 (20) | 0 (0) | 4 (22) | 1 (5) | 1 (16) | 1 (16) |
| School problem | 30 (100) | 4 (13) | 18 (100) | 3 (16) | 6 (100) | 1 (16) |
| Neurotic symptoms | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 0 (0) |
| Sexual problem | 2 (6) | 0 (0) | 4 (22) | 2 (11) | 2 (33) | 1 (16) |
| Psychotic symptoms | 0 (0) | 0 (0) | 2 (11) | 0 (0) | 3 (50) | 1 (16) |
| Physical complain | 6 (20) | 2 (6) | 4 (22) | 2 (11) | 1 (16) | 1 (16) |
| Hysteric symptoms | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 1 (16) | 0 (0) |
| Drug abuse | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 1 (16) | 0 (0) |

of suicidal behavior was less. Thalassemic patients react to disease related stress with a variety of coping strategies and some of the most frequently used are mal-adaptive, indicating feelings of helplessness and hopelessness.^[10]

There is a need to take care of anxieties and worries of thalassemic adolescents and parents^[6] to prevent the development of further emotional and adjustment problems. Moreover, the challenge of adjustment to a chronic illness can provide an excellent opportunity for the adolescents to master crucial skills such as emotion regulation and problem solving. Psychosocial support will increase compliance to treatment, as shown by data.^[11] So to prevent psychological burden due to disease early intervention is necessary which requires at least quarterly psychological evaluation by a psychologist.

Conclusion

Our findings support the hypothesis that psychosocial problems are more in thalassemic adolescents and young adults. Behavioral disorders were common in age group of 10-15 years, mood disorders in age group of 15-20 years and psychotic and sexual problems in 20-25 years age group. School problems were found in all patients.

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