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Evaluation of Behavioral Risk Factors and Functional Disorder in Thalassemia Major Patients and Their Families, a Retrospective Cross-Sectional Study

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ABSTRACT

Introduction: Thalassemia can lead to psychological and emotional problems and functional disorders in patients and their families. The present study has investigated the behavioral risk factors and functional state of patients with thalassemia major (TM) and their families. **Methods**: The present cross-sectional study has been conducted on 61 children with TM (case) and 61 healthy children (control) admitted to Amirkabir Hospital, Arak, Iran. In addition to the clinical, behavioral, and demographic information checklist for each person, the behavioral evaluation questionnaire was filled out for their patients and families. **Results**: The mean age ± standard deviation (SD) of the patients in the case and control groups were 19.86 ± 9.86 (range: 5-54) and 18.50 ± 8.8 (range: 5-50), respectively. According to CBCL in children under 16 years, there were no significant differences in terms of withdrawal/depression (P=0.143), somatic complaints (P=0.07), rule-breaking behaviors (P=0.20), and aggressive behavior (P=0.28), while the attention problems (P=0.03), anxiety and depression (P=0.001) and thought problems (P=0.01) were significantly higher in these patients. In over 16-year-old patients, anxiety and depression were significantly higher than the healthy group (P=0.001). Siblings of patients didn't show more psychological problems (P>0.05). In contrast, the anxiety and depression in mothers (P<0.0001 - P=0.02) and fathers (P=0.01 - P=0.02) of patients were significantly more than average individual's parents. **Conclusion**: Thalassemia major leads to some behavior problems in patients, influencing different aspects of their lives. It is essential to provide more supportive care with psychological intervention in these patients and their parents.

Keywords: Beta-Thalassemia major, Mental Disorders, Behavioral problems, Family

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INTRODUCTION

Thalassemia is the most common hereditary anemia resulting from the defective production of hemoglobin protein chains (1). It has been divided into the two types of minor and major according to the different hereditary patterns. The heterozygote form or thalassemia minor is a mild disease resulting from one defective gene copy. In contrast, the homozygote form of the disorder leads to thalassemia intermedia and thalassemia major (TM), which is the severe form (2). Thalassemia minor is usually asymptomatic and requires no specific treatment; however, TM requires regular blood transfusions and lifelong supportive care (3-5). This disorder is highly prevalent in Iran, with about 20,000 individuals with TM and approximately 2-3 million (4% of the population) carriers. Patients with TM need repeated blood transfusions to ensure survival, but the interventions might cause numerous complications (6).

Adolescents make the country's future, and unfortunately, 10-15% of them suffer from a chronic disease. Therefore, providing lifelong healthcare services and treatment for these patients is extremely important. Patients with TM are almost dependent on the medical staff to survive for the rest of their lives.

When severe and chronic diseases are indicated in a family, it will trigger behavioral risk factors and functional disorders, leading to mental and emotional problems for both the patients and the family members. It might also result in poor familial performance in daily affairs. Children who suffer from chronic deficiencies would have poor performances in society; the parents feel the burden of the situation and sometimes show impulsive behavior that may negatively affect the children's

mental health (7-9). Thus, making the parents aware of their role in providing a relaxed atmosphere for their families would be helpful (10-14).

The present study has investigated the behavioral risk factors and functional disorders of patients with TM and their family members to figure out the prevalence of different psychological disturbances to better manage the patients with TM.

MATERIAL AND METHODS

The present cross-sectional study was conducted on patients with TM, their parents, and their siblings at the hematologic clinic of Amirkabir Hospital, Arak, Iran. Ethical principles were observed and followed based on the ethical code approved by the Ethics Committee of Arak University of Medical Sciences (IR.ARAKMU.REC.93-173-10). We performed the sampling through the available non-probability method, and the final sample size included 61 children with TM and 61 healthy children admitted to Amirkabir Hospital, Arak, Iran. The case and control groups were matched in terms of age and gender. The exclusion criteria were the existence of a known psychiatric disorder before the diagnosis of TM and the subject's reluctance to continue the study.

Initially, the researcher interviewed the parents of all the 122 children and asked them to fill in the questionnaires, which were in Persian and standard versions. If just one of the parents came to the hospital, all questions were sent to another parent after receiving the relevant address and telephone number. Then the children were examined at the clinic. If the parents were illiterate, the interviewer read the questions and recorded the answers after receiving their permission and the informed consent.

We assessed the prevalence of depression and anxiety among the patients using the Beck Depression Inventory and the Beck Anxiety Inventory. Their mental disorders were also considered using the Child Behavior Checklist (CBCL), which their parents completed. The Beck Inventory is a standard questionnaire containing 21 questions, and each of them consists of four categories with 0 to 3 points (15). The questionnaire can also detect major depression and categorize it from mild to severe based on the relevant score. Scores less than 8 represent the absence of anxiety, scores 8 to 15 indicate mild anxiety, scores 16 to 26 represent moderate anxiety, and scores higher than 26 are categorized as severe cases of stress (15). The Child Behavior Checklist is a formal assessment scale similar to behavioral assessment techniques. It includes questions designed for girls and boys aged 4-18 to measure their skills and social adaptation. The checklist is one of Steinbach's experience-based systematic forms that must be filled by the parents, caregivers or anyone else who meets the child in a family environment and knows them perfectly. The respondent was initially asked several questions to measure the child's competencies and several open questions about the child's illness and disability which measure the respondent's primary concern for the child and their opinion about the best traits of children. The questionnaire also classified the children's emotional, behavioral, and social problems. It included 113 questions, and the respondent was asked to answer the questions based on the child's behavioral model within the past six months, using the scoring system of 0 = inaccurate, 1 = somewhat or sometimes correct, and 2 = entirely or often correct (16). Patients were also divided into two groups, over 16 years old and under 16 years old, according to the CBCL checklist contract (17).

Table 1. The mean age and frequency of gender in patients

	Case	Control	P-value
Age(y)	Mean ±SD: 19.86 ± 9.86 Min-Max: 5-54	Mean ±SD: 18.50±8.8 Min-Max: 5-50	0.1
Gender (%)	Male: 29(47.54%) Female: 32(52.46%)	Male: 31(50.81%) Female: 30(49.19%)	0.09

The variables included the prevalence rate of depression, anxiety, and insomnia in patients with TM and their parents, behavioral problems in patients with TM, behavioral issues in Siblings of patients with TM, the prevalence rate of depression, anxiety, and insomnia in the healthy children's parents, healthy children's behavioral problems, and behavioral problems of the siblings of the children without TM.

Statistical analysis

Statistical analyses were performed with the Graph Pad software (Version 6). The unpaired Student t-test was applied to compare ages and other parametric data in the two groups. Furthermore, we used the Chi-square test to compare genders. The criterion for statistical significance was $p < 0.05$. The results were reported as the mean ± standard deviation (SD).

RESULTS

The mean age ± SD of the patients in case and control groups were 19.86 ± 9.86 (range: 5-54) and 18.50 ± 8.8 years (range: 5-50), and the prevalence of male gender in case and control groups were 47.54% (29 individuals) and 50.81% (31 individuals) respectively. Comparison of age and gender showed that there were no significant differences between the two groups in terms of age (P=0.1) and gender (P=0.09) (Table 1).

According to the CBCL in the children under the age of 16, the results showed that in the case group, the Mean ± SD of withdrawal/depression was 3.10 ± 2.3, Somatic Complaints was 3.15 ± 2.2, anxiety and depression were 5.21 ± 2.3, social problems was 3.36 ± 1.9, thought problems was 3.31 ± 2.0, attention problems was 2.63 ± 1.6, rule-breaking behaviors was 4.15 ± 2.7, and aggressive behaviors was 4.47 ± 3.4, and in the control group the variables mentioned above were; 2.05 ± 1.9, 1.94 ± 1.8, 2.68 ± 1.7, 1.94 ± 1.6, 1.78 ± 1.3, 1.52 ± 1.3, 3.05 ± 2.5, 3.47 ± 2 respectively. Moreover, there were no significant differences between the groups in terms of withdrawal/depression (P=0.14), somatic complaints (P=0.07), rule-breaking behaviors (P=0.20), and aggressive behavior (P=0.28). On the other hand, the attention problems (P=0.03), anxiety and depression (P=0.001), social problems (P=0.01), and thought problems (P=0.01) were significantly higher in patients (age < 16 years) with TM compared with the healthy children (Table 2).

The mean ± SD of anxiety and depression for those over the age of 16 was 12.88 ± 7.5 and 14.45 ± 8.5 in the case group and 8.95 ± 7.5 and 10.04 ± 7.9 in the control group. The results indicated that anxiety and depression were (P=0.001) signifi-

cantly higher in patients with TM (Table 3).

According to the CBCL, the Mean ± SD of brothers of the case group in terms of withdrawal/depression was 2.57 ± 2.6, somatic complaints were 2.28 ± 2.2, anxiety and depression were 2.71 ± 2.4, social problems was 2.7 ± 2.1, thought problems was 2.7 ± 2.1, attention problems was 2.4 ± 2.1, rule-breaking behaviors was 2.85 ± 2.1, and aggressive behaviors was 3.0 ± 2.1, and in the control group were 2.14 ± 2.1, 1.85 ± 1.6, 1.90 ± 1.7, 1.84 ± 1.7, 1.84 ± 1.7, 1.74 ± 1.6, 2.56 ± 2.5, 2.95 ± 2.4 respectively (Table 4). For sisters of the case group, the Mean ± SD of withdrawal/depression was 2.6 ± 2.0, somatic complaints were 2.48 ± 1.8, anxiety and depression were 4.65 ± 4.5, social problems was 1.4 ± 0.8, thought problems was 2.80 ± 2.4, attention problems was 1.80 ± 1.4, rule-breaking behaviors was 1.20 ± 1, aggressive behaviors was 4.0 ± 3.2 but in the control group, the variables mentioned above were 2.35 ± 1.8, 1.95 ± 1.8, 2.30 ± 1.5, 1.80 ± 1.2, 1.7 ± 1.2, 2.0 ± 1.4, 2.45 ± 1.9, 3.05 ± 1.8 respectively (Table 5).

The results showed that there were no significant differences between the siblings of the two groups in terms of withdrawal/depression (P=0.6, P=0.7), somatic complaints (P=0.5, P=0.8), anxiety and depression (P=0.3, P=0.06), social problems (P=0.6, P=0.5), thought problems (P=0.5, P=0.1), attention problems (P=0.3, P=0.7), Rule-breaking behaviors (P=0.7, P=0.1), and aggressive behaviors (P=0.9, P=0.3).

Based on the Beck questionnaire, the mean ± SD of anxiety and depression in brothers and sisters were 14.1 ± 1.2, 13.5 ± 1.6 in the case group and 10.8 ± 1.6, 9.5 ± 1.8 in the control group; which means that there were no significant differences between the two groups in this regard (P>0.05), (Fig1).

The mean ± SD score of anxiety were respectively 14.5 ± 1.3 and 11.6 ± 1.2 for the mothers in the case and the control groups; and for the fathers, they were 15.1 ± 1.3 and 10.5 ± 1.2. The mean ± SD of depression were respectively 13.8 ± 1.7 and 11 ± 1.5 for the mothers in the case and control groups, and 13.6 ± 1.6 and 10.5 ± 0.8 for the fathers in the case and control groups. Therefore, the rates of anxiety and depression were remarkably higher in the mothers (P<0.0001 - P=0.02) and fathers (P=0.01 - P=0.02) of the children with TM compared with the parents of healthy children (Fig 2).

DISCUSSION

The present study examined the prevalence of behavioral and functional problems in patients with TM and their family members. Based on the results, the patients with TM under 16 had a higher prevalence of attention problems, anxiety and depression, and thought complications than healthy children. For the patients with TM over 16, anxiety and depression were significant psychological disorders.

Furthermore, anxiety and depression were commonly reported in the parents of patients with TM, while there were no significant behavioral and functional problems in their siblings.

These results showed that Thalassemia major would lead to behavior problems in patients, which negatively influences their lives. Consequently, more health care with psychological interventions in this group of patients and their parents are needed. The most common causes of these psychological consequences are financial problems, treatment complications, and disabilities resulting from the disease.

Table 2. The mean scores of CBCL in individuals under 16 years

	Case	Control	P-value
Withdrawal/ Depression	3.10±2.3	2.05±1.9	0.143
Somatic Complaints	3.15±2.2	1.94±1.8	0.079
anxiety and depression	25.21±2.3	2.68±1.7	0.001
Social problems	3.36±1.9	1.94±1.6	0.018
Thought Problems	3.31±2.0	1.78±1.3	0.012
Attention problems	2.63±1.6	1.52±1.3	0.031
Rule-breaking behaviors	4.15±2.7	3.05±2.5	0.209
Aggressive behaviors	4.47±3.4	3.47±2.0	0.284

Table 3. The mean scores of CBCL in individuals under 16 years

	Case	Control	P-value
Anxiety	12.88±7.5	8.95±7.5	0.001
Depression	14.45±8.5	10.04±7.9	0.001

Table 4. The mean scores of CBCL in individuals under 16 years

	Case (N=7)	Control (N=21)	p-value
Withdrawal/ Depression	2.57±2.6	2.14±2.1	0.667
Somatic Complaints	2.28±2.2	1.85±1.6	0.598
anxiety and depression	2.71±2.4	1.90±1.7	0.341
Social problems	2.7±2.1	1.84±1.7	0.681
Thought Problems	2.7±2.1	1.84±1.7	0.578
Attention problems	2.4±2.1	1.74±1.6	0.324
Rule-breaking behaviors	2.85±2.1	2.56±2.5	0.759
Aggressive behaviors	3.0±2.1	2.95±2.4	0.964

Table 5. The mean scores of CBCL in individuals under 16 years

	Case (N=5)	Control (N=20)	p-value
Withdrawal/ Depression	2.6±2.0	2.35±1.8	0.798
Somatic Complaints	2.48±1.8	1.95±1.8	0.879
anxiety and depression	4.65±4.5	2.30±1.5	0.063
Social problems	1.4±0.8	1.80±1.2	0.520
Thought Problems	2.80±2.4	1.7±1.2	0.168
Attention problems	1.80±1.4	2.0±1.4	0.786
Rule-breaking behaviors	1.20±1	2.45±1.9	0.182
Aggressive behaviors	4.0±3.2	3.05±1.8	0.387

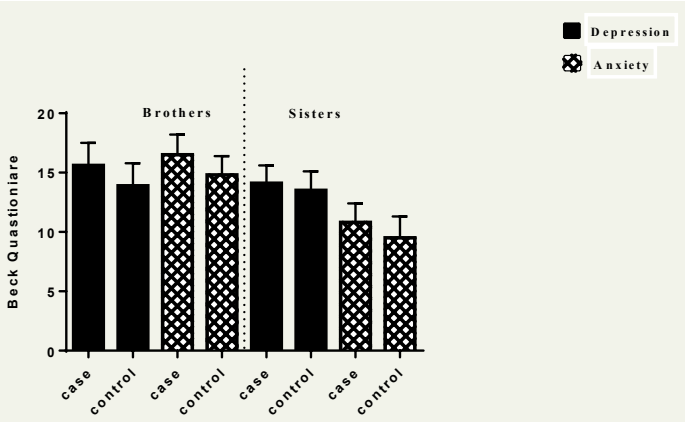

Figure 1. Compare of Beck questionnaire in siblings of individuals. There were no significant differences between the two groups (P>0.05).

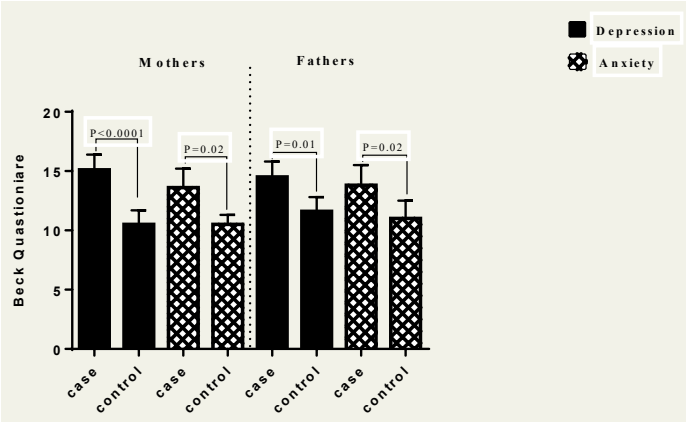

Figure 2. Compare of Beck questionnaire in mothers and fathers of individuals.

these patients and their families.

Huda Gharaibeh et al. (19) also noted the importance of psychological support in patients with TM and their families. They assessed the psychological disorders in TM patients, and similar to the present study, there was a high prevalence of anxiety and family adjustment disturbance in patients with TM.

Furthermore, a study by Behdani et al. (20), conducted on the psychological disorders in 60 patients with TM, showed the high prevalence of anxiety and depression and lower quality of life in these patients compared with the healthy population was compatible with our results.

Based on the other studies on the assessment of mood and anxiety disorders, unpleasant emotional circumstances were more prevalent in patients with chronic diseases than in the general population; however, there are not enough studies on the prevalence of psychological disorders for each chronic disease (21-23).

The study by Habeeb Yousi et al. (24) on the prevalence of depression in 100 Iraqi patients with TM showed the high prevalence of depression among them. It seems that screening for depression should be performed on patients with TM.

The study of Usyle et al. (25) on the sense of hopefulness among 133 Turkey's patients with TM showed no significant differences between the patients with TM and the healthy population in terms of hopefulness. While in our study, the patients with TM and their parents had psychological disorders (18-20). The differences between the results may be related to the genetics of patients.

Similar to the present study, a cross-sectional study by Maheri et al. (26) showed anxiety and depression disorders and lower quality of life in the patients with TM.

Hashemi et al. (21) on the prevalence of depression and anxiety in patients with hemophilia and β-TM indicated that depression and anxiety were more common in the patients than in healthy people.

Ultimately, 2 points should be noted about the patients who suffer from chronic diseases such as TM. Firstly, behavioral risk factors and functional disorders resulting from being involved with a condition for life can ultimately affect their personal and social performances. Secondly, a patient with a chronic disease who regularly needs health care, medications, or other medical procedures can negatively affect the mental lation, failure of independence, maladaptive coping strategies, compromised physical ability, and limited life opportunities in patients with chronic diseases, including TM, are inevitable, it would be a cautious approach for such patients to be evaluated through counseling with therapists and related specialists; as a result, if there were routine follow up for this study population, it would not only figure out the prevalence of different psychological disturbances but also help us understand the course of these issues.

Due to the current study's limitations, more studies with larger sample sizes are needed to assess the psychological effects of TM and such diseases on the patients and their families.

Based on the result of the current study and the limited number of studies in this regard, although the recommended psychological interventions in children with TM and their parents seem to be helpful, further studies are recommended to assess more items and risk factors such as the severity of the disabilities, different organs' involvement, family literacy level, patients' intelligence level, and family economy level for a complete result.

CONCLUSION

Compared with healthy people, patients with TM usually face behavioral risk factors and functional disorders, especially depression and anxiety disorders. Furthermore, their family members, particularly their parents, would be involved and suffer from anxiety and other mental problems. Anxiety, depression, and thought problems are shown to need special attention as they can directly affect the primary disease course and, if not treated, lead to severe complications. This group of patients and their families need further attention, such as counseling sessions and psychological assessments.

ETHICAL CONSIDERATION

Ethical principles were observed and followed based on the ethical code approved by the Ethics Committee of Arak University of Medical Sciences (IR.ARAKMU.REC.93-173-10).

CONFLICT OF INTRESETS

There are no conflicts of interest in terms of the present manuscript.

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Author Contribution: AE has supervised this paper from the beginning. AK had the role of acquisition of data and drafting the manuscript. BSF had the role of acquisition and interpretation of data. AyE has devoted herself to the study design, and it's manuscript. SAS had the role of final edit and review of this paper. RRA has helped in analyzing the data as well as the final review. All authors read and approved the final manuscript.

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