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Psychosocial problems in patients with thalassemia and their siblings referred to Bam Special Diseases Center A comparative study (2019)

Running title: Statins and relapse after orthodontic treatment

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Abstract

Introduction:

Psychosocial problems of patients and family members of beta thalassemia patients are among important issues. This study was performed to determine the psychosocial problems of patients with thalassemia and their siblings compared to the control group.

Methods:

This descriptive-comparative study was carried out using structural interviews and a checklist of behavioral symptoms of children. Samples of this study were 236 children, including 59 thalassemic children aged 4 to 16 years, 59 siblings of these without chronic disease as the case group and 118 healthy children with the same age condition as control group. Data were analyzed using the tests of chi-square, McNemar, Wilcoxon, and independent- paired t-tests.

Results:

The mean age of the children in this research was 9.91 with a standard deviation of ±3.41%. The mean of psychosocial problems was 17.54% based on the questionnairewith a standard deviation of ±10.10%. 37.3% of thalassemic children, 20.3% of siblings and 20.8% of control group had social psychological

problems. Chi-square test shows that psychosocial disorders in children with thalassemia was more than control group ($p < 0.05$).

Conclusion:

The families of patients with thalassemia, especially the siblings of the patients mentioned, should be considered in the care plan for these patients; this is because of the high prevalence of psychosocial problems in this group compared to healthy children.

Keywords: Psychosocial problems, Thalassemia patients, Specific diseases, Bam.

Introduction

B-Thalassemia is a single gene disorder resulting from globin chain synthesis impairment through the mutation or deletion of globin chains (1). The World Health Organization has known thalassemia as the most common chronic genetic disorder in 60 countries. More than 2.5% of people are carriers of hemoglobinopathy and are a major health problem in 71% of 229 countries. Around 300-400 thousand births are born annually with hemoglobin deficiency and more than 95% of these births occur in Asia, India and the Middle East. Nowadays, it spreads across the Mediterranean and Middle East regions, Southeast Asia and from southwestern Europe to the Far East. It is seen in large parts of Africa (2, 3). Beta thalassemia is a common genetic disorder in Iran and there are currently more than 26,000 people in the country with thalassemia patients; with this number of thalassemic patients, Iran has first rank in the world in proportion to the whole population of the world. In Iran, 85% of patients are under the age of 18 and about 700 billion riyals are spent annually on patients with thalassemia major (4). It is estimated that 3% of the world population and 5% of the Iranian population carry beta thalassemia gene and the most common form of thalassemia in Iran is beta thalassemia. More than 2 million and 800,000 carriers live in Iran and about 800 people are added annually to major cases. The beta thalassemia gene frequency is high in Iran and is scattered throughout the country; but in the Caspian Sea marginal area and the Persian Gulf, Oman Sea, the provinces of Isfahan, Kohkiluyeh and Boyer Ahmad, Khuzestan, Fars and South Kerman, it has the highest prevalence. Beta-thalassemia gene expression is approximately 8-10% in the south and southeast of our country, as reported (5). Like Other Patients with Chronic Diseases, Beta-Thalassemia Patients are affected by the Emotional and Behavioral Disorders (6). Arab et al reported in 2012 that 20.4% of children with thalassemia and 12% of their healthy siblings and 7.9% of Healthy children in the same age group have had psychosocial problems (7). Yengi et al. (2014) reported that 11.1% of siblings of patients with thalassemia were depressed; this was 61.1% for mothers and 27.8% for fathers. This indicates the emotional vulnerability of family members, especially mothers (6). On the other hand, beta thalassemia is a chronic disease that causes psychosocial problems in patients and family members (7). Beta-thalassemia major affects the emotional status, daily activities, family experiences, and occupational capabilities of patients and their caregivers due to the complex and heavy lifelong treatment protocol (6). A chronic illness causes financial and emotional problems that affect each family member (8). Children with chronic hematological disorders can be exposed to anxiety and depression due to social problems such as separation from the family, limited social activity, physical and emotional deformities, death anxiety and limitations in school activities and play (6). Psychological function (depression and anxiety) of similar activities and sibling cognitive development score of people with a chronic illness are lower than that of siblings of patients with thalassemia (7). Children with chronic hematological disorders can be exposed to anxiety and depression due to social problems such as separation from the family, limited social activity, physical and emotional deformities, death anxiety and limitations in school activities and play. There are studies of early psychological maturity in children with chronic disease that they cope with the psychological and medical consequences of this disease (9). Concerns about premature death and the idea that their lives are different from others lead to aggression, communication problems, loneliness, and depression (10). Because seeking and treating thalassemia-related psychosocial disorders to improve the quality of life of patients and their families are important, therapists need to be aware of the negative psychological effects of chronic illnesses on patients, siblings, and patients. Thus, they design intervention programs for patients, siblings, and families with chronic illnesses (6, 11, and 12). Given that for the augmentation of awareness and planning, we need to identify the psychosocial

problems of the individuals and their families, psychological counseling for people with mental, social and family problems is one of the goals of mental health (5). We designed this research determine the psychosocial problems in thalassemic patients and their siblings in Bam. Based on the results of this research and similar ones, we can plan intervention programs for prevention and solving problems.

Procedure: This is a descriptive comparative study performed in year 2019. The sample consisted of 236 children in three groups. The first group consisted of 59 children with thalassemia in the age range of 4 to 16 years, the second group of 59 siblings in the same age group without any chronic illness and the last group of 118 healthy children referred to health centers in Bam. They were randomly selected from health centers and were assigned as the control group with the same age range. The inclusion criteria were having brother or sister with thalassemia who had a maximum age difference of 3 years from the child. The duration of the disease is very similar in terms of the diagnosis of the disease in early life and the need for blood transfusions at this age range. Only one brother or sister of the patient with thalassemia is selected for the case group. The control and case groups were matched for age, absence of other chronic diseases in the family. Data were collected using a two-part questionnaire including demographic characteristics and PSC (Pediatric Symptoms Checklist). This checklist is a standard tool for screening children and identifying their social and psychological problems that are widely used in first-level preventive care. This checklist has 35 questions categorized as never, sometimes and often and scored with 0, 1, 2, respectively.

The overall score is obtained by summing the scores for every 35 questions. For children 6 to 16 years old, the score 28 and above indicates psychosocial disorders. For children aged 4 and 5, the score 24 or higher indicates a disorder. In adolescents over 16, a score 30 and above indicates a disorder. Unanswered items are considered 0 and the questionnaire containing more than 4 questions with no answers is non-valid. The results of previous studies have shown that more than 2.3 positive cases had a moderate to severe disorder and 95% were able to detect healthy cases by questionnaire. Pediatricians and other health professionals use this checklist to diagnose and treat psychosocial problems in children. The PSC is an appropriate screening tool for designing health development programs. The reliability and validity of the tool were confirmed with Cronbach's alpha (0.90) (7). By visiting the parents of children, preferably mother, the questionnaire demanded participation; then ensuring the confidentiality of information and the fact that the lack of participation has not any impact on the treatment of their children, the questionnaires were completed by them. If they were not literate for completing questionnaire, it was completed by interview. We obtained the ethical code IR.MUBAM.REC.2019.038 for this study from the Research and Technology deputy of Bam University of Medical Sciences. After transferring the questionnaire information to software SPSSv23, data were analyzed using descriptive and inferential statistics and Chi-square, ANOVA, and t-tests.

Results

The mean age of children in this research was 9.91 with a standard deviation of ±3.41. It was 9.83 in the thalassemic group of children with a standard deviation of ±3.45, 10.80 in the thalassemia siblings with a standard deviation of ±3.70 and 9.10 in the healthy children group with a standard deviation of ±3.34. There were 187 male children, of whom 31 (52.5%) were in the thalassemia group, 33 (55.9%) siblings and 125 (53%) were in the healthy children group. 33 (55.9%) of thalassemic children, 30 (50.8%) of siblings, and 104 (44.1%) of healthy children were elementary students. No statistically significant difference was observed using Chi square and Wilcoxon tests ($p < 0.05$) (Table 1). Most of the fathers in the thalassemia group were educated in junior high school (37.3%), diploma and over in the control group (62.3%); in the mothers of thalassemia group, most of them were educated in junior high school (37.3%) and in control groups they were diploma and over (37.3%). Most fathers were freelance in thalassemia group (62.7%) and healthy children group (64%). The difference was significant. Most of the fathers had free jobs that in thalassemic group, it was 62.7% and in the healthy children group 65.7%. In the control group, most of fathers were employees but in thalassemic group, there was no father as employee. Most mothers in both groups were housekeepers, with 96.6% in the thalassemia family and 78.4% in the control group, respectively. There were also more employed mothers in this group (Table 2). History of psychiatric illnesses in thalassemic children was 15.3%, in their siblings 6.8% and in healthy children 9%. These findings indicate that it was more common in

general in thalassemia patients' family (afflicted child and sibling). In addition, the difference between groups using chi-square and McNemar tests was not significant (P <0.05). The mean of psychosocial problems was 17.54% with standard deviation of ±10.10; 37.3% of thalassemic children, 20.3% of siblings and 20.8% of control group had psychosocial problems. Chi-square test showed that the prevalence of psychosocial disorders in children with thalassemia was higher than the control group (p <0.05). Independent t-test showed that the score of psychosocial disorders scale in children with thalassemia was significantly higher (p> 0.05). But the chi square test showed that the percentage of psychosocial disorders in siblings of children with thalassemia was not higher than the control group (p> 0.05). The score of psychosocial disorders scale in siblings of children with thalassemia were not significantly higher (p> 0.05). McNemar test showed that the percentage of psychosocial disorders in siblings of children with thalassemia was lower than those with thalassemia (p <0.05). Independent t-test showed that the score of social psychosocial disorders scale in children with thalassemia was significantly higher (p <0.05) (Table 3). Psychosocial problems in thalassemic children were not significantly correlated with demographic variables and none of these variables were predictors of psychosocial problems.

Table 1: Absolute and relative Frequency of the Units under Study by Child Gender and Education and their Comparison

Variable		Group					
		Thalassemia		Sibling		Control	
		Number	Percentage	Number	Percentage	Number	Percentage
Gender	Male	31	52/5	26	44/1	125	53/0
	Female	28	47/5	33	55/9	111	47/0
Comparison of children with thalassemia with control group		P=0.953					
Comparison of siblings of children with thalassemia with control group		P=0.141					
Comparison of children's siblings with children with thalassemia		P=0.487					

Variable		Group					
		Thalassemia		Sibling		Control	
		Number	Percentage	Number	Percentage	Number	Percentage
Child education	Illiterate	0	0.	2	3/4	10	4/2
	Primary	33	55/9	30	50/8	104	44/1
	Junior high school	11	18/6	15	25/4	50	21/2
	Diploma and higher	1	1/7	2	3/4	7	3/0
	Without response	14	23/7	10	16/9	65	27/5

Variable	Group					
	Thalassemia		Sibling		Control	
	Number	Percentage	Number	Percentage	Number	Percentage

Comparison of children with thalassemia with control group	P=0.654					
Comparison of siblings of children with thalassemia with control group	P=0.9595					
Comparison of children's siblings with children with thalassemia	P=0.819					

Table 2: Absolute and relative Frequency of the Units under Study by Mother Education and Education and their Comparison

Variable		Group				Statistical test
		Thalassemia		Control		
		Number	Percentage	Number	Percentage	
Mother education	Illiterate	17	8/28	8	4/3	
	Primary	15	4/25	23	7/9	
	Junior high school	22	3/37	51	6/21	
	Diploma and higher	5	5/8	151	0/64	
	Without response	0	.0	3	3/1	

Variable		Group				Statistical test
		Thalassemia		Control		
		Number	Percentage	Number	Percentage	
Mother job	Free	57	6/96	185	4/78	57
	Primary	1	7/1	14	9/5	1
	Without response	1	7/1	35	8/14	1

Table 3: Absolute and relative Frequency of the psychosocial disorders in three groups and their Mean

Variable		Group					
		Thalassemia		Sibling		Control	
		Number	Percentage	Number	Percentage	Number	Percentage
psychosocial disorder	Yes	37	62/7	47	97/7	187	79/2
	No	22	37/3	12	20/3	49	20/8
	Mean & standard deviation	± 10/69 20/40		± 9/66 15/13		± 9/96 17/10	

Discussion

Our research shows that thalassemic children have a higher level of psychosocial problems than normal children and their siblings. This is expected in thalassemia patients. Numerous studies (13, 14) have

confirmed and reported that patients with thalassemia have psychosocial disorders; this may be due to the chronic nature of thalassemia, medical costs and the expectation of premature death. They need treatment, psychological counseling and further intellectual and social supports (7). The results of these studies also indicate the necessity of screening programs for early diagnosis and treatment of psychosocial disorders in thalassemia patients as well as the use of knowledge and expertise of psychiatrists and clinical psychologists in thalassemia centers (15). The results of the present study showed that the percentage of psychosocial disorders in siblings of children with thalassemia was lower than the control group. This is not in line with the results of the study conducted by Yango et al. (16) and Hooshmandi et al. (14) and Arab et al. (7). Ghaffari et al examined the relationship between social support and depression in diabetes patients. The results showed a significant and reverse relationship between social support and depression in diabetes patients. That is to say, one can find that the depression in diabetic patients was associated reversely with the social support (17). Another study suggests that some patients had tension by others' support; this increases their dependence on families. Some patients also express that they are not satisfied with the support of family members due to lack of knowledge and sufficient information about the disease. In fact, they are afraid that the support of members of the family will result in the risk due to non-effective information (14). Other studies have shown that families are the most important source of social support for thalassemia patients. One of the major issues that cause the parents of these patients to be worried is that others judge on their child without proper knowledge of their child's illness, which can cause parental frustration (18). As a result, the way in dealing with by the family will be the faith in God and trust in solving the problems of patient care and treatment. The family relies on the religion in dealing with disease. So 85% of families are adapting successfully to their child's disease (19). In terms of parents' education in the thalassemia group (both parents), 37.3% of them had junior high school. Ghazanfari et al (2011) in their study noted that parents of children with thalassemia are not aware of the nature of the disease; despite the hereditary disease, the number of their children was one 8 children and a number Families had more than one child afflicted (20). By father's occupation, there was no employee in the thalassemic group. Most of them (62%) had free jobs. While control group fathers (62%) were diplomas or higher. Yazdi et al (2007) also note in their study that families with thalassemic children are often faced with many economic difficulties such as transportation costs and drug preparation (19). According to the findings of this study, we can say that families, as well as a person with thalassemia, are faced with economic problems in order to obtain more information about the patients, especially new treatments, and need support of supportive systems. While highly educated and employed people usually have interpersonal relationships, they have the opportunity to be present in different communities and organizations, and subsequently more opportunities to find friends supporting them. High income can also be a great source of high social support (21). In terms of occupation, most of the mothers in the thalassemia family were 96.6% housekeepers. This is not an unexpected result, since in our society most of the care is given by the mother to the child (20). Parents of children with special needs, especially mothers, are often at home and almost isolated because of the need to take full care of their children. Also, these parents, compared to the parents of normal children, instead of thinking about the issues of such jobs, which improve their lives, are constantly involved in the problem of their children and the problems of his presence in their lives. They neglect issues such as their physical and mental health. They are increasingly in need of social support in order to enhance the quality of life. These parents need support in relation to their children's educational and rehabilitation interventions, with the help of rehabilitation institutions the amount of child support is increased and the burden on parents is reduced (22, 23, 24). The average history of psychiatric diseases in children with thalassemia was higher than that of their siblings and healthy children. A study done in India showed that patient and families of patients suffer from the psychological problems. Also, in comparison the severity of problems showed that psychological problems make pain for the families more than other problems. As a result, 54.4% of families had moderate psychological problems (19). Findings the study of Gholizadeh showed that mean anxiety, depression, aggression, and shyness were more than healthy groups in thalassemia patients (22). In general, studies have shown that people who have social support and have lower inter-personal conflicts, resist in the face of life's pressures and have less symptoms of depression or disturbance of mental suggest (14).

The results also showed that there was no significant relationship between psychosocial problems in thalassemic children and any of the demographic variables. None of these variables was predictors of psychosocial problems. This result contrasts with the results of Khamoushi et al. (25), Pour Mansouri (26). The difference in results may be due to the difference in research design and tools of data collection; but one should keep in mind that the samples of research are not homogeneous in terms of the type of disease, culture, age etc. Probably these factors play an important role in different results and contradictory studies.

Conclusion

Despite the importance of psychologists in helping to identify and solve emotional problems, the demand for their counseling has not attracted any attention. In this regard, activities like education and counseling programs by TV, the use of centers in access in order to increase knowledge and information of parents seem necessary. The Association of Thalassemia can use the psychological cooperation in the care centers for the easy access of the families. The findings showed that despite the importance of social support in the reduction of tension and copping better with the problems, social support was the lowest way of using by families. This is perhaps a result of a lack of awareness about the protection centers of the public and their non-willingness to receive direct assistance from others as well as the shortage of formal and unofficial supportive centers (19).

Limitations

There were limitations in our study. To assess psychosocial problems in patients, we used a psc checklist that is valid only for screening purposes. Therefore, the use of clinical examination for definitive diagnosis of psychosocial problems is recommended for similar future studies.

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