

The Association between Behavioral Problems with Self-Esteem and Self-Concept in Pediatric Patients with Thalassemia

Seyed Mohamad Kazem Nourbakhsh¹, Minoo Atamanesh^{1*}, Mohammad Effatpanah², Mona Salehi³, Morteza Heidari^{4,5}

Abstract

Objective: High prevalence of behavioral and psychological disorders in children with thalassemia can be associated with a decrease in the self-esteem of patients and can completely alter the person's self-concept. The aim of this study was to determine the prevalence of behavioral problems and its relationship with self-esteem and self-concept in patients with thalassemia major aged 6 to 18 years.

Method: In a cross-sectional study, 30 patients with thalassemia major at the age of 6 to 18 years were enrolled. behavioral problems, self-esteem, and self-concept were evaluated by the child's behavioral check list at the ages of 6 to 18 years (CBCL 6-18), the Coopersmith's Self-Esteem Inventory, and the Piers-Harris Children's Self-Concept Scale.

Results: A total of 10.0% of patients had behavioral disorders, 3 (10.0%) desirable self-esteem, 15 (50.0%) moderate self-esteem, and 12 (40.0%) poor self-esteem. There was a strong but adverse correlation between behavioral disorder score and both self-esteem score (correlation coefficient equal to -0.886, p value = 0.001) and self-concept score (correlation coefficient equal to -0.498, p value = 0.001), and thus those patients with behavioral disorder had less appropriate self-esteem and self-concept.

Conclusion: The incidence of behavioral disorders is associated with decreased self-esteem and poor self-concept in these patients. Therefore, improvement in behavioral disorders can be expected by improving self-esteem and self-concept in such patients.

Key words: *Self-Esteem; Self-Concept; Thalassemia*

1. Department of Pediatric Hematology and Oncology, School of Medicine, Tehran University of Medical Sciences, Tehran, Iran.
2. Department of Pediatrics, Imam Khomeini Hospital, School of Medicine, Tehran University of Medical Sciences, Tehran, Iran.
3. Psychiatry and Psychology Research Center, Tehran University of Medical Sciences, Tehran, Iran.
4. Pediatrics Center of Excellence, Department of Pediatric Neurology, Children's Medical Center, Tehran University of Medical Sciences, Tehran, Iran.
5. Department of Pediatric Neurology, Vali-e-Asr Hospital, Imam Khomeini Hospital Complex, Tehran University of Medical Sciences, Tehran, Iran.

*Corresponding Authors:

Address: Department of Pediatrics, Vali-e-Asr Hospital, Imam Khomeini Hospital Complex, Bagherkhan Street, Tehran, Iran, Postal Code: 1419733141.

Tel: 98-21 66581529; Fax: 98-21 66581529, Email: minoo.atamanesh@gmail.com

Article Information:

Received Date: 2019/12/30, Revised Date: 2020/04/15, Accepted Date: 2020/04/11



Thalassemia major is a severe disorder characterized by jaundice, anemia, failure to thrive hepatosplenomegaly, and the skeletal deformities, which can lead to the characteristic facial appearance of the disease. Mental health and social function in these patients can be affected by the skeletal deformity, delayed puberty, and growth retardation, and difficulty of treatment (eg, lifelong transfusion and chronic iron chelation treatment) (1).

Physical issues such as chronic anemia, bone deformities, changes in growth and shortness of height, postponement of physical maturity, heart failure, cardiac arrhythmias, and impaired liver function as well as unpleasant treatment regimens all affect different components of the patient's life (2, 3).

Frequent absenteeism from school, reduced academic performance, limitation in social relationships, feelings of dependency on others, feeling disadvantaged in doing some routine affairs, sadness and loss due to lack of health, concerns about early death, and the thought that their lives are different from others lead to depression and reduce the patients' self-esteem (4,5).

Previous studies indicated a higher psychopathological prevalence among children with thalassemia than among controls as well as a correlation between specific psychiatric disturbance and physical illness (6). Adolescence is an important and prominent step in social and psychological development. Chronic diseases affect the interactions of adolescents with the physical and social environment and change their relationship with others. Loneliness is a common experience in adolescents, but when this feeling is repeated, it has a devastating effect on the physical, mental, and emotional health. In patients with thalassemia, loneliness begins in childhood and increases with age, leading to depression in adolescence. Teens who feel lonelier feel more depressed and have more emotional problems (7).

Adolescence is a critical period in the development of self-confidence and the formation of self-concept of the individual due to important physical and emotional changes. Self-esteem and feeling of value are the attributes that persons have towards themselves. Losing body control, repeated examinations, and painful physical or physical diagnostic or therapeutic measures may reduce self-esteem. Chronic diseases have a negative effect on the level of person's hope. Hope is a symbol of mental health and the ability to believe in a better feeling in the future. However, disappointment is the opposite of hope and the main features and manifestations of depression. Disappointment has a negative effect on the health and social relationships of an individual and is an important factor for depression and suicide. Adolescents with thalassemia have some degree of frustration and low self-esteem (8). It seems that thalassemia not only affects physical functioning, but also affects mental, psychological, and social performance. Knowledge about the prevalence and

factors associated with mental and psychological problems in adolescents with thalassemia, especially self-esteem and negative self-concept, will play a key role in improving the quality of life of affected adolescents. The aim of this study was to determine the prevalence of behavioral problems and its relationship with self-esteem and self-concept in patients with thalassemia major aged 6 to 18 years.

Materials and Methods

In a cross-sectional study, patients with thalassemia major at the age of 6 to 18 years old referring to the Children's Medical Center from May 2019 to May 2020 were enrolled. Samples were selected by stratified random sampling. The sample size was calculated as 30 according to below formula (significant level: 0.05, power: 80%):

$$N = ([Z_{\alpha} + Z_{\beta}] / C)^2 + 3$$

$$C = 0.5 * \ln \left(\frac{[1 + r]}{[1 - r]} \right)$$

Children between 6 to 18 years old with a previous diagnosis of major beta thalassemia who were referred to the Children's Medical Center and were willing to take part in the study were included. The exclusion criteria were children without a precise diagnosis and patients whose families were unwilling to cooperate as well as children with a history of other medical or psychiatric disorders. The evaluation information was classified into 4 categories: (1) Baseline information includes demographic characteristics, medical and drug history as well as laboratory data, which were all extracted from the hospital recorded files. (2) Information related to behavioral disorders was collected using the child's behavioral check list at the ages of 6 to 18 years (CBCL 6-18). The CBCL checklist is a tool that measures the competence and behavior of the child through parents or those who know the child well using a scoring range of 0 to 3. This scale consists of 113 items and gives a general score as a general behavioral problem. This scale involves 2 broad dimensions (external and internal problems) and 8 limited syndromes (anxiety/depression, withdrawn, somatic complaints, social problems, thought problems, attention problems, rule-breaking behavior and aggressive behavior). The scores of this scale include the raw scores and the scores transmitted to the T score, so that the T score higher than the 90th percentile would be considered as a behavioral disorder (In this study, the T score higher than 64 was considered as a criterion for determining behavioral problems.) (9). In similar studies, the construct validity of this questionnaire was obtained to be appropriate with a validity index ranging 0.59 to 0.86 (10). In Ahadi et al study, Cronbach's alpha for both external and internal dimensions were 0.59 and 0.65, respectively. Cronbach's alpha coefficient was obtained for 8 subscales in the range between 0.48 and 0.75 (11). (3) To assess children's self-esteem, the Coopersmith's Self-Esteem

Inventory (SEI) was used. The 51 item self-esteem questionnaire has 9 subsamples (general, social, familial, and academic self-esteem scale) and a subsample of the liars, and its responses are in the form of "yes" and "no" options. This questionnaire describes the opinions or reactions of an individual and is provided to measure feedback on oneself in social, family, school, and personal areas. Studies in Iran and abroad indicate that this test is valid and reliable. Herz and Gullone (12) have reported a Cronbach's alpha of 0.88 for the overall test score. (4) Children's self-concept was evaluated by the Piers-Harris Children's Self-Concept Scale. This scale is designed to measure the level of self-concept of children and adolescents and is summarized in the attitude and perception of the individual towards oneself. The questionnaire includes 80 questions, containing a personal report on how children and young people feel about themselves. This scale has 6 dimensions, including behavior; school situation and cognitive and mental status; physical appearance and attributes; anxiety; relief society (popularity); and happiness and satisfaction. To assess the validity of the test, Pears assessed 52 normal fourth-grade boys and girls that achieved a validity coefficient of 0.44 for both genders (13). The questionnaire has been also validated in Iran with the reliability and validity coefficients of 0.90 and 0.91, respectively (14). In the present study, after obtaining written consent from the child and his/her parents and in a meeting, the questionnaires were filled in and the results were entered into the statistical file for analysis. For data analysis, chi-square test, student t test, and its non-parametric equivalents (Mann Whitney U test) were used, if necessary. To determine the association between the quantitative variables, the Pearson's or Spearman's correlation tests were employed. The association of behavioral problems with self-esteem and self-concept was finally assessed using the multivariable linear regression model. For the statistical analysis, the statistical software SPSS version 16.0 for windows (SPSS Inc, Chicago, IL) was used. P values of 0.05 or less were considered statistically significant.

Results

In this study, 30 patients with β -thalassemia in the age range of 6 to 18 years old were enrolled. In terms of sex distribution, 56.7% were boys and 43.3% were girls. The mean age of patients was 9.77 ± 2.71 years, and the mean duration of the disease was 1.90 ± 0.88 years. In terms of the level of education in fathers, 20.0% were undergraduate, 50.0% had a diploma, and 9 (30.0%) had an academic degree. Also, among mothers, 3.3% were illiterate, 46.7% had undergraduate education, 36.7% had a diploma, and 13.3% had college degrees. Regarding the types of behavioral disorders based on the CBCL checklist, the mean total score of behavioral disorder was 52.73 ± 8.16 in the range of 38 to 66. After taking a T score above 64 for the diagnosis of behavioral disorder, we found that 10.0% had behavioral disorders.

The mean score for different components of behavioral disorder ranged from somatic complaints (2.0) to aggressive behavior (11.3) (Table 1). The presence of behavioral problem was independent to gender ($p = 0.842$), disease duration ($p = 0.085$), and fathers' education level ($p = 0.424$). But an adverse association was revealed between behavioral disease score and patients' age ($r = -0.409$, $p = 0.025$). Also, higher score for behavioral disease was adversely related to mothers' educational level ($p = 0.017$) (Table 2).

The mean score of self-esteem in patients with thalassemia major was 29.55 ± 5.81 . Only 3 cases (10.0%) had desirable self-esteem, 15 (50.0%) had moderate self-esteem, and 12 (40.0%) had poor self-esteem. The score for self-esteem was independent to gender ($p = 0.300$), age (0.092), and disease duration ($p = 0.244$). However, both fathers ($p = 0.050$) and mothers ($p = 0.001$) with higher education level had children with higher score of self-esteem.

The mean score of self-concept in patients with thalassemia was 38.93 ± 7.67 . The self-concept in such patients was independent to gender, age, and disease duration as well as to educational level of both fathers and mothers (Table 2).

There was a strong but adverse correlation between behavioral disorder score and self-esteem score (correlation coefficient equal to -0.886 , p value 0.001). In other words, patients with behavioral disorder had much less self-esteem than those without behavioral problems (Figure 1). Similarly, there was a strong adverse association between behavioral disorder score and self-concept score (correlation coefficient equal to -0.498 , p value to 0.001), and thus those patients with behavioral disorder had less appropriate self-concept (Figure 2). Based on multivariate linear regression model, the association of behavioral disease with both self-esteem and self-concept was independent to baseline parameters such as gender, age, duration of illness, and parenting education (Tables 3 and 4).

Table 1. Scores of behavioral Disorders in the Field of Major Thalassemia

Behavioral problem	Mean \pm SD
Anxious/Depressed	7.78 \pm 2.32
Withdrawn/Depressed	2.23 \pm 1.41
Somatic Complaints	2.03 \pm 0.81
Social Problem	3.33 \pm 2.25
Thought Problems	3.97 \pm 2.14
Attention Problems	7.40 \pm 2.35
Rule-Breaking Behavior	8.07 \pm 1.80
Aggressive Behavior	11.37 \pm 2.27
Other problems	5.47 \pm 1.83
Total score	52.73 \pm 8.16

Table 2. Behavioral Disorder, Self-Esteem and Self-Concept based on Underlying Indices

Index	Behavioral disorder	self-esteem	self-concept
Gender			
Male	53.00 ± 7.86	28.59 ± 5.05	41.24 ± 8.02
Female	52.38 ± 8.85	30.85 ± 6.66	36.00 ± 6.25
Age, year	Correlation (r = -0.409)	Correlation (r = 0.313)	Correlation (r = -0.357)
Disease duration	Correlation (r = -0.341)	Correlation (r = 0.219)	Correlation (r = 0.016)
Father education			
Undergraduate	55.50 ± 10.95	27.87 ± 3.11	41.67 ± 4.93
Diploma	50.80 ± 8.10	27.87 ± 3.11	38.13 ± 8.15
Academic	54.11 ± 6.07	33.44 ± 8.81	38.44 ± 8.66
Mother education			
Undergraduate	53.07 ± 9.21	26.43 ± 2.41	41.14 ± 8.64
Diploma	51.90 ± 8.88	29.36 ± 2.69	36.64 ± 6.05
Academic	51.50 ± 5.97	41.50 ± 6.35	35.50 ± 6.66

Table 3. Correlation between Behavioral Problem and Self-Esteem in a Multivariable Linear Regression Model

Item	Beta	SE	T score	P value
behavioral problem	-0.890	0.097	-9.208	< 0.001
Gender	-0.940	1.492	-0.630	0.535
Age	-0.201	0.347	-0.577	0.569
Disease duration	-0.806	1.125	-0.716	0.481
Father education	-0.985	1.265	-0.779	0.444
Mother education	0.837	1.185	0.706	0.487

Table 4. Correlation between Behavioral Problem and Self-Concept in a Multivariable Linear Regression Model

Item	Beta	SE	T score	P value
behavioral problem	-0.429	0.154	-2.781	0.011
Gender	1.626	2.379	0.683	0.501
Age	0.465	0.554	0.840	0.410
Disease duration	-0.989	1.794	-0.552	0.587
Father education	-1.136	2.016	-0.564	0.579
Mother education	-2.936	1.889	-1.554	0.134

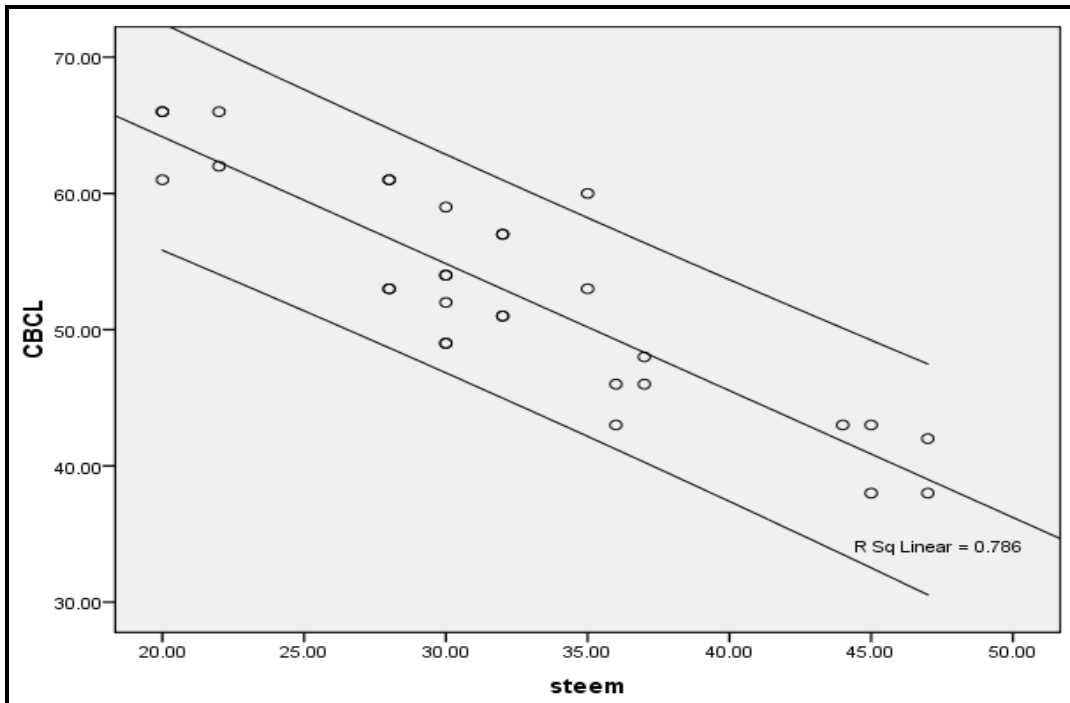


Figure 1. Linear Correlation between Behavioral Disorder Score and Self-Esteem

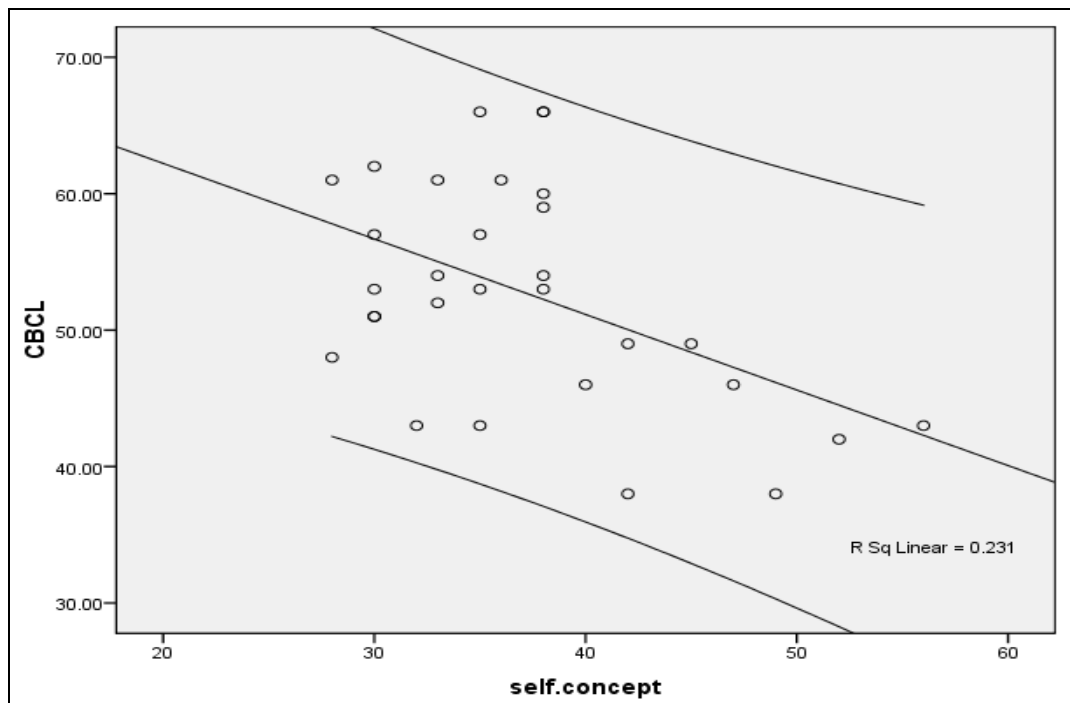


Figure 2. Linear Correlation between Behavioral Disorder Score and Self-Concept

Discussion

The high prevalence of psychological disorders is predictable due to physical disabilities and social impairments in patients with β -thalassemia. High prevalence of behavioral and psychological disorders can be associated with a decrease in the self-esteem of patients and completely alter the person's self-concept. We primarily evaluated the prevalence of behavioral disorders and clarified self-esteem and self-concept among school-aged (6 to 18 years) patients with β -thalassemia; and in the second step, we assumed that behavioral disorders can be related to the alterations in self-esteem and the self-concept in such patients. First, we found that 10% of patients with β -thalassemia had a behavioral disorder. In this regard, the prevalence of behavioral disorder had an inverse correlation with the patient's age and education level of the patient. In other words, older people and those having mothers with more education were at a lower risk of behavioral disorders. First, it seems that when the patient gets older and goes to school and is exposed to a variety of psychological education and counseling, especially in educational centers, they can control their behavioral abnormalities. Most of such training and counseling can be provided by parents who are trained and have more knowledge. Therefore, raising parents' awareness about various aspects of behavioral disorders in a patient with thalassemia can reduce the risk of developing and progression of such disorders. In the present study, what was considered as a variety of behavioral disorders mainly included anxiety/depression, somatic complaints, and social complaints, thought problems, attention problems, rule-breaking behaviors, and aggressive behaviors. In this regard, the highest incidence was related to aggressive behavior followed by rule-breaking behaviors and then anxiety/depression. What has been found in various studies about the prevalence of behavioral disorders in patients with thalassemia major is partly consistent with our findings. According to Pourmansouri et al, patients with major thalassemia have poor quality of life and a high percentage of patients have depression, anxiety, and moderate to severe stress (15). In Hosseini et al's study, somatic complaints, hypersensitivity to interactions, depression, anxiety, and psychosis were common psychological findings in thalassemia patients aged 15 to 25 years (16). In a study by Hongally et al, 32% of patients with β -thalassemia had a type of behavioral disorder that was far higher than ours. Also, he found that aggressive behavior was the most commonly disrupted behavior among these children (17).

Few studies have been performed on the self-esteem and self-concept of patients with β -thalassemia. The results of our study showed a high prevalence of low self-esteem (in 40% of patients) and a poor self-concept in these patients. It seems that these patients, especially at an early age, do not have enough knowledge and attitude about aspects of self-esteem (awareness of their values)

and self-concept (the mentality and feeling of one's self towards oneself), since entering larger societies may result in good self-esteem in patients. Moreover, patients with more educated families will face more awareness of different aspects of self-esteem and self-concept .

The main objective of this study was to assess the relationship of behavioral disorders with self-esteem and self-concept in β -thalassemia patients aged 6 to 18 years. In this regard, we found that increased risk of behavioral disorders has been accompanied by a decrease in both self-esteem and self-concept. In fact, the lack of self-esteem and self-concept can exacerbate behavioral disorders. As shown clearly in the study by Tomaj et al, participating in collaborative activities and targeted games (rather than depression, depression, or antisocial disorder) can lead to a significant increase in self-esteem, which is consistent with our findings (18). Also, in Kiani et al's study, cognitive-behavioral therapies have been effective in decreasing disappointment, increasing self-esteem, and family self-esteem levels in patients (19). Therefore, explaining the causal relationship between patients' behavioral quality on the one hand and levels of self-esteem and self-concept on the other can lead to improvement of behavioral disorders by strengthening self-esteem and self-concept and vice versa.

Limitation

One of the limitations of this study was small sample size and lack of a precise medical and family history of the participants.

Conclusion

According to the findings of this study, significant proportions of patients with thalassemia has behavioral disorders and have self-esteem and poor self-concept issues. The incidence of behavioral disorders is associated with decreased self-esteem and poor self-concept in these patients. Therefore, improvement in behavioral disorders can be expected by improving self-esteem and self-concept in such patients.

Acknowledgment

The authors are grateful to the Children's Medical Center staff and all of the patient's families who cooperated in this study.

Conflict of Interest

None.

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