IAAOJ International Anatolia Academic Online Journal

ORIGINAL ARTICLES / ARAŞTIRMA MAKALESİ

FACTORS AFFECTING LEVELS OF HOPEFULNESS IN ADOLESCENTS WITH THALASSEMIA MAJOR*

Derya Demir Uysal[1], Hüsniye Çalışır[2]

[1]Lecturer, Sıtkı Koçman University, Faculty of Health Sciences, Nursing Division, Pediatric Nursing Department. [2]Prof. Dr., Adnan Menderes University, Nursing Faculty, Pediatric Nursing Department, Aydın, Turkey

Corresponding Author: Derya Demir Uysal

e-mail: deryademiruysal@gmail.com

Bu çalışma Adnan Menderes Üniversitesi ASYO 13003 proje numarası ile desteklenmiştir.

ABSTRACT

The aim of this study was to compare the hopefulness levels of adolescents with thalassemia major (TM) and healthy adolescents, and to determine the impact of some sociodemographic and disease-related characteristics of adolescents with TM on their hopefulness. This cross-sectional and correlational study was conducted in 112 adolescents with TM and 121 healthy adolescents, a total of 233 adolescents. The study sample was selected using the convenience sampling method. While the mean Hopefulness Scale for Adolescents (HSA) score of the adolescents with TM was 1769.9±290.5, it was observed that the mean HSA score of the healthy adolescents was 1824.5±267.9, but the difference was not found to be statistically significant (t=1.491, p=0.137). It was found that, after controlling for the other factors, the father's educational status impacted the hopefulness score of adolescents with TM and the

educational status of a father with an elementary/middle school education had an adverse effect on the hopefulness score (t = -2.601, p=0.011). In this study no difference was found between the hopefulness levels of adolescents with TM and those of healthy adolescents. The only sociodemographic factor that had an impact on the hopefulness of the adolescents with TM was their father's level of education. Nurses can provide professional help and support to the thalassemic patients who experience hopelessness, and can activate social support systems to help patients cope with such feelings.

Key Words: Adolescent, hopefulness, pediatric nursing, thalassemia major

TALASEMİ MAJORLÜ ERGENLERİN UMUT DÜZEYLERİNİ ETKİLEYEN FAKTÖRLER

ÖZET

Bu çalışmanın amacı, talasemi majörlü ergenler ile sağlıklı ergenlerin umut düzeylerini karşılaştırmak ve talasemi majörlü ergenlerin bazı sosyodemografik özellikleri ile umut düzeylerinin ilişkisini belirlemekti. Bu tanımlayıcı ve ilişki arayıcı çalışma, talasemi majörlü 112 ergen ile 121 sağlıklı ergen olmak üzere toplam 233 ergen ile yapılmıştır. Araştırma örneklemi olasılıksız örnekleme yöntemi kullanılarak seçilmiştir. Talasemi majörlü ergenlerin umutluluk ölçeği puan ortalaması 1769.9 ± 290.5 iken, sağlıklı ergenlerin puan ortalaması 1824.5 ± 267.9 olarak belirlenmiştir fakat istatistiksel olarak anlamlı farklılık bulunmamıştır (t=1.491, p=0.137). Diğer faktörler kontrol altına alındıktan sonra baba eğitim durumunun talasemi majörlü ergenlerin umutluluk puanını etkileyen faktör olduğu ve babanın ilkokul/ortaokul mezunu olmasının umutluluk puanını olumsuz etkileyen bir faktör olduğu

bulunmuştur (t = -2.601, p=0.011). Talasemi majörlü ergenlerin umutluluk ölçeği puan ortalaması sağlıklı ergenlerin umutluluk ölçeği puan ortalamaları arasındaki istatistiksel olarak anlamlı fark bulunmamıştır. TM'li ergenlerin umutlulukları üzerinde etkisi olan tek sosyodemografik faktör babalarının eğitim düzeyiydi. Hemşireler, umutsuzluk yaşayan talasemi hastalarına profesyonel yardım ve destek sağlayabilir ve hastaların bu tür duygularla başa çıkmasına yardımcı olmak için sosyal destek sistemlerini etkinleştirebilirler.

Anahtar Kelimeler: Ergen, Umutluluk, Çocuk hemşiresi, Talasemi majör,

INTRODUCTION

The thalassemias are a diverse group of inherited hemoglobin disorders characterized by a reduced synthesis of the globin chains and result in varying degrees of anemia due to hemolysis and ineffective erythropoiesis (1). β-thalassemia major is a life-long disorder requiring intensive treatment regimens, including frequent blood transfusions and daily chelation therapy (2). Thalassemias are a serious health problem worldwide (3). The highest prevalence of β-thalassemia is seen in populations living in Asia, the Mediterranean, Transcaucasia, the Indian Subcontinent, and the Far East (4,5). In Turkey, according to the results of a national hemoglobinopathies study, β-thalassemia major represents approximately 83% of the total thalassemia patient population, although the prevalence of β-thalassemia carriers was found to be 2.1% overall in Turkey, the epidemiological data demonstrated regional differences, with a higher prevalence in coastal areas (6,7).

Patients with thalassemia major (TM) are affected by serious complications particularly due to post-transfusional iron overload, which is an important cause of morbidity and mortality in individuals with thalassemia (4,7). Iron chelation therapy is considered an

essential component of thalassemia management, removing the iron which accumulates due to regular blood transfusions (3, 6, 8, 9). Iron overload contributes to increased risk of liver cirrhosis, heart failure, and endocrine abnormalities, while ineffective erythropoiesis and hemolysis contribute to multiple complications, including splenomegaly, extramedullary hematopoiesis, pulmonary hypertension, and thrombosis (1,7). Heart failure is still the most important cause of death, despite great improvement in the clinical management of thalassemia (10).

Having a chronic disease such as TM may affect the hopefulness levels of adolescents because of issues that include worrying about the future, frequent hospital visits for blood transfusions, body dysmorphic disorder, self-perception as different from peers due to delayed growth, and stress and psychiatric disorders stemming from the complications of the disease (major depression, generalized anxiety disorder, etc.) (11,12,13). A lifetime filled with difficulties lead these patients to experience various psychosocial issues. Psychological and psychosocial problems (anxiety, depression, low quality of life, low self-esteem, loneliness, and hopelessness) may be observed in 20%–80% of patients with TM (9,13). Compared to their peers, children and adolescents with TM have lower quality of life and higher anxiety and depression levels (11,14,15,16).

There are various studies in the literature which focus on children and adolescents with thalassemia from the perspectives of quality of life (9, 15, 16, 17), adaptation to the illness (7, 18), psychosocial problems (11, 12, 19, 20, 21, 22, 23), and loneliness and self-esteem (24). A few studies, however, probe the hopefulness/hopelessness levels of adolescents with TM (24, 25), But they have only looked into the hopefulness of adolescents with TM. There is also a need to explore the factors that contribute to levels of hopefulness.

The purpose of this study was to compare the hopefulness levels of adolescents with TM and healthy adolescents and to determine the impact of some sociodemographic and disease-related characteristics of adolescents with TM on their hopefulness levels.

METHODS

Design and participants

This cross-sectional and correlational study was conducted from 2012 and 2014 with a group of adolescents with TM and another of healthy adolescents. The study sample comprised 133 adolescents with TM aged 12–18, who were being monitored at the pediatric hematology polyclinics of hospitals in four provinces in Turkey's Aegean Region, and also 1.418 healthy adolescents of the same age group enrolled in an elementary school and a high school, again in the Aegean Region. This study was conducted at five state hospitals in the southwest of the Turkey. The study sample was selected using the convenience sampling method. Adolescents were eligible to participate in our study if they had no problems with their sight or hearing, and had not received a psychiatric diagnosis in the previous month (anxiety disorder, depression, etc.) and were not being treated for such a condition.

The number of individuals to be recruited into the study sample was determined by a power analysis using the Minitab 15 program with 0.80 (80%) at a 95% confidence interval, an effect size of 0.50, and α=0.05. This found that at least 64 adolescents with TM and 64 healthy adolescents should be included in the study, meaning a total of 128 adolescents. Twenty-one adolescents with thalassemia were excluded (rejected or could not be reached). Twelve healthy adolescents who were not given consent to participate by parents were also

excluded. Finally, the study was completed with 112 adolescents with TM and 121 healthy adolescents, a total of 233 subjects.

Instruments

The participants completed a sociodemographic questionnaire. This form was developed by the researchers in accordance with the literature (13, 26). That for adolescents with TM comprised 24 items that sought the characteristics of adolescents diagnosed with thalassemia and their families (age, gender, educational status, etc.) and information about TM. The questionnaire for the healthy adolescents comprised 15 items on the descriptive characteristics of healthy adolescents and their families (9, 13, 26).

The Hopefulness Scale for Adolescents (27), the Turkish version of which was tested for validity and reliability (26), was used to determine the adolescents' hopefulness scores. The HSA is a 24-item visual analog instrument that was created to measure an adolescent's degree of future orientation at the time of the measurement (26). With possible responses that range from "I never think in these terms" at one end of the scale to "I always think in these terms" at the other, the respondent is asked to place a mark on a horizontal line of 100 millimeters on the statement that best applies to him/her. Each item thus receives a score of between 0 and 100. All item scores are summed to calculate a total scale score. Scale scores range between 0 and 2.400, higher scores signifying higher levels of hopefulness (26). The HSA has been used to determine the hopefulness levels of healthy, substance-dependent adolescents and others being treated for emotional and mental disorders or cancer (26,27,28). The internal consistency coefficient for the hopefulness scores of the adolescents participating in this study was α=0.86.

Data collection

The data of the adolescents with TM were collected first. These adolescents were being monitored in pediatric hematology polyclinics, they fulfilled the inclusion criteria and their families were informed about the study. The rules for the completion of the questionnaires were explained to the participants in a suitable, quiet room, and then the sociodemographic data questionnaire was filled out by the first researcher using a face-to-face interview method while the HSA was completed by the adolescents themselves. The HSA was completed in 8-10 minutes. Blood transfusion should be performed on patients with thalassemia at least once a month (generally, once every three weeks). As blood transfusions are performed every day or on specific days in the pediatric hematology units of certain institutions, data were collected in polyclinics on dates determined by pediatric nurses and adolescents together.

The adolescents in the healthy adolescents group were recruited by age, to match the adolescents in the TM group. They too were aged 12–18 and were enrolled in an elementary school in the province of Muğla. They were given an explanation of the study. The students were provided informed consent and data collection forms to give to their parents and were asked to return them if parental consent was given. The rules for the completion of the data collection forms were explained in a quiet room to the parents who had given written consent, and the sociodemographic questionnaire was filled out in face-to-face interviews while the adolescents filled out the HSA themselves.

Ethical considerations

Written permission was obtained for the study from the institutions in which the study was conducted and from the Adnan Menderes University Medical Faculty Clinical Research

Ethics Committee (Number: 2012/82). Written approval was obtained from the Ministry of National Education Muğla Provincial National Education Directorate. In addition, necessary written approvals were obtained from the offices of the chief physicians in hospitals where the study was conducted. The adolescents and their parents provided written consent.

Data analysis

The data were analyzed with the SPSS 17.0 program for Windows. They were analyzed using descriptive statistics, the student t-test, the Chi-squared test, the Mann-Whitney U test, the Kruskal-Wallis test, one-way ANOVA, and multiple regression analysis. To determine similarities between the thalassemia and healthy adolescent groups, the student t-test was used for continuous variables and the Chi-squared test for categorical variables. These data were analyzed with the Kolmogorov-Smirnov test to determine the distribution.

Since differences were found between groups in terms of mothers' educational status, fathers' educational status, the loss of relatives to thalassemia and blood transfusion frequency ($p < 0.05$), these four factors were included in the regression model. Dummy coding was performed for the independent variables included in the logistic regression analysis. Accordingly, mothers' elementary/middle school diploma was coded as 1 while high school diploma or a higher degree was coded as 0. Similarly, fathers' elementary/middle school diploma was coded as 1 while high school diploma or a higher degree was coded as 0. Losing a relative to thalassemia was coded as 1 while not losing a relative was coded as 0. Receiving a blood transfusion every two weeks was coded as 1 while receiving a transfusion every three or four weeks was coded as 0.

The correlation analysis of the factors in the model showed that there was a positive but weak correlation between fathers' and mothers' educational status ($r = 0.50$). No linear

relationship was found between the other factors. The Cronbach's alpha (α) test was used to calculate the reliability coefficients of the adolescents' scores on the HSA. The results, at a confidence interval of 95% and values at $p<0.05$, were accepted to be statistically significant.

RESULTS

Findings on the Descriptive Characteristics of Thalassemia Major and Healthy Adolescents

More than half of the adolescents with TM and close to half of the healthy adolescents were girls. Close to half of the adolescents in both groups were in the age group 12–14, and more than half were high school students. It was found that the two groups were similar in terms of gender, age, and educational status ($p>0.05$). A significant majority of both groups lived in a nuclear family. Close to half of the adolescents with TM and three-quarters of the healthy adolescents had one sibling. More than half of both the adolescents with TM and the healthy adolescents said that their household expenditure was equal to the family's income. There was a statistically significant difference between the two groups in terms of family type, number of siblings and perceived income level (Table 1).

Table 1. Distribution by the sociodemographic characteristics of adolescents with thalassemia major and healthy adolescents (n=233)

Sociodemographic Characteristics	Groups					
	With Thalassemia Major (n=112)		Healthy (n=121)			
	n	%	**n**	%	df†	x^2, p value
Gender						
Female	58	51.8	60	49.6	1	$x^2=0.113$ p=0.737
Male	54	48.2	61	50.4		

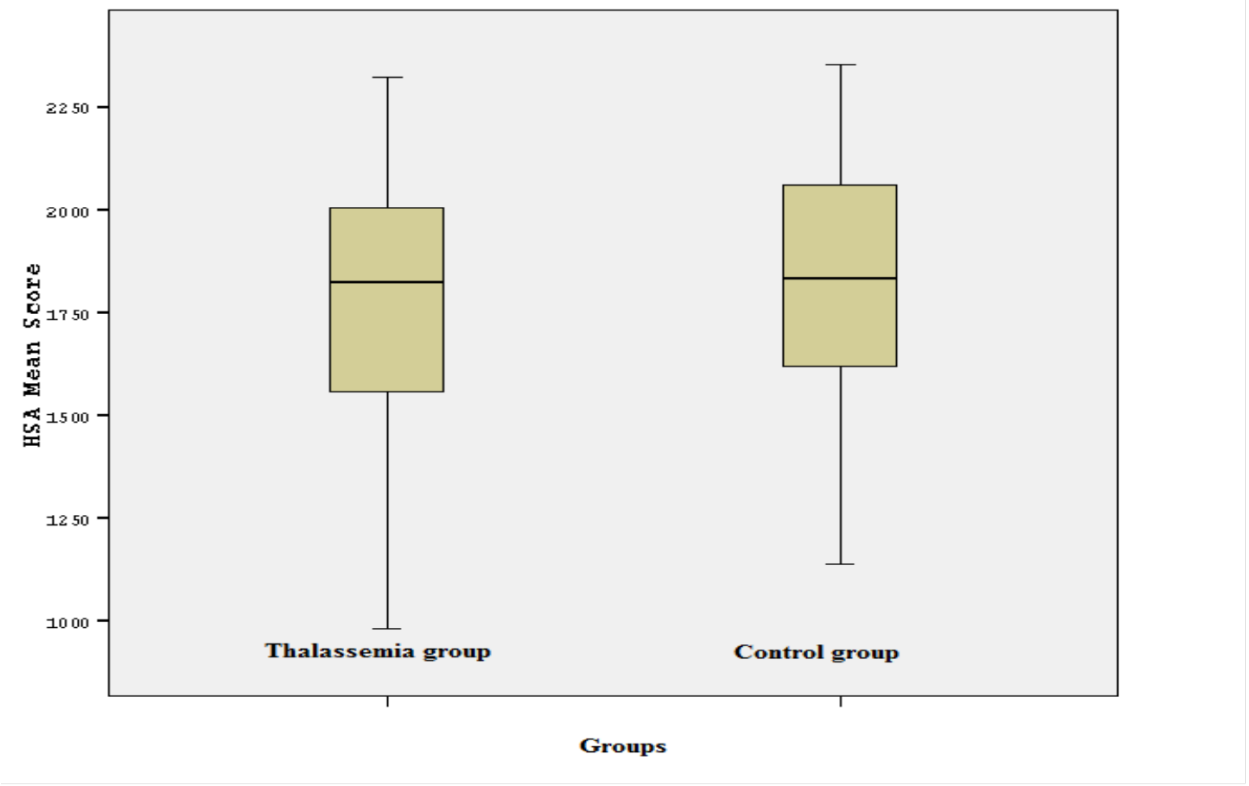
Age group						
Ages 12-14	50	44.6	55	45.4		$x^2 = 0.149$
Ages 15-16	33	29.5	33	27.3	2	p=0.928
Ages 17-18	29	25.9	33	27.3		
Education						
Middle school	50	44.6	55	42.5	1	$x^2 = 0.015$
High school‡	62	55.4	66	54.5		p=0.901
Family type						
Nuclear family§	95	84.8	115	95.0	2	**x^2 =5.728**
Extended family	17	15.2	6	5.0		**p=0.017***
Number of siblings						
No siblings	31	27.7	22	18.2		**x^2 = 19.598**
One sibling	50	44.6	87	71.9	2	**p=0.000***
Two or more siblings	31	27.7	12	9.9		
Perceived income status						
Income lower than expenditure	37	33.1	10	8.3		
Income equal to expenditure	61	54.4	73	60.3	2	**x^2 = 27.355** **p=0.000***
Income greater than expenditure	14	12.5	38	31.4		

**p<0.05.* †df: degree of freedom, ‡Two individuals studying at the university were added to the high school group. x^2 : Chi-square test.

Findings Regarding the Mean Scores of Hopefulness Scale of Adolescents

Graph 1 demonstrates the participants' hopefulness scale scores. While the mean HSA score of the adolescents with TM was 1769.9±290.5, it was observed that the mean HSA

score of the healthy adolescents was 1824.5±267.9 but the difference was not found to be statistically significant (t=1.491, p=0.137).



Graph 1. Hopefulness scores of adolescents with thalassemia major and healthy adolescents

Comparison of the mean scores of hopefulness scale according to some sociodemographic characteristics of parents

It was determined that the groups were homogeneous in terms of their parents' age and the fathers' employment status, while they presented a significant difference in terms of mothers' employment status and the kinship between the parents (Table 2).

Table 2. Distribution by the sociodemographic characteristics of the parents of adolescents with thalassemia major and healthy adolescents (n=233)

Sociodemographic Characteristics	With Thalassemia Major (n=112)		Healthy (n=121)		df†	**x^2, p value**
	n	**%**	**n**	**%**		
Mother's age group						
Ages 30-39	63	56.3	66	54.6	2	x^2 = 2.146 p=0.342
Ages 40-49	41	46.6	51	42.1		
Ages 50-59	8	7.1	4	3.3		
Father's age group						
Ages 30-39	24	21.4	27	22.3	2	x^2 = 0.594 p=0.743
Ages 40-49	74	66.1	75	62.0		
Ages 50-64	14	12.5	19	15.7		
Mother's educational level						
Elementary/middle school	96	85.7	63	52.1	1	x^2 = 30.385 p=0.000*
High school/university	16	14.3	58	47.9		
Father's educational level						
Elementary/middle school	86	76.8	44	36.4	1	x^2 = 38.532 p=0.000*
High school/university	26	23.2	77	63.6		
Mother's employment status						
Employed	16	14.3	32	26.4	1	x^2 = 5.258 p=0.022*
Housewife	96	85.7	89	73.6		
Father's employment status						
Employed	96	85.7	105	86.8	1	x^2 = 0.055 p=0.814
Retired	16	14.3	16	13.2		
The kinship between parents						
Yes	37	33.0	8	6.6	1	x^2 = 26.061 p=0.000*
No	75	67.0	113	93.4		

*p<0.05

While the mean HSA score of adolescent girls with TM was 1726.5±304.1, that of adolescent boys was 1816.6±270.1. The difference between the two was not found to be significant. Additionally, there was no significant difference in terms of age group or educational status. This study, there were no differences between mean HSA scores

according to the gender, age, family type, number of siblings, perceived income status, parents' age, and the employment status or educational level of mothers of adolescents with TM (Table 3).

Table 3. HSA mean scores by the sociodemographic characteristics of the adolescents with thalassemia major (n=112)

Sociodemographic Characteristics	n	HSA Mean Score Mean ± SD	t/ x^2_{KW}/ U/Z F, p value
Gender			
Female	58	1726.5 ± 304.1	t=1.65
Male	54	1816.6 ± 270.1	p=0.101
Age group			
Ages 12-14	50	1780.9 ± 307.1	x^2_{KW} = 1.277
Ages 15-16	33	1733.0 ± 270,1	p=0.528
Ages 17-18	29	1793.1 ± 289.3	
Education			
Middle school	50	1735.9 ± 306.3	t=1.117
High school*	62	1797.5 ± 276,5	p=0.267
Family type			U = 589.0
Nuclear family	95	1749.1 ± 301.5	Z = [-1.772]
Extended family	17	1886.5 ± 185.6	P=0.076
Number of siblings			
No siblings	31	1847.1 ± 284.5	F= 1.543
One sibling	50	1736.0 ± 301.9	p=0.218
Two or more siblings	31	1747.5 ± 271.5	
Perceived income status			
Income less than expenditure	37	1691.1 ± 279.9	x^2_{KW} = 4.205
Income equal to expenditure	61	1811.2 ± 300.8	p=0.122
Income greater than expenditure	14	1798.6 ± 243.3	

*Two individuals studying at the university were added to the high school group.

While the mean HSA score of adolescents who had relatives sick with TM was 1782.5±283.1, which of those who had no relatives with TM was 1762.1±296.7 No statistically significant difference was found between them. A surprising finding was that the mean HSA score of adolescents who lost a family member or relative to TM (2014.4±322.2)

was strikingly higher than the mean HSA score of adolescents who had not suffered such losses (1758.5±285.5). This difference was statistically significant. In terms of the method of chelation therapy applied to the adolescents with TM, it was seen that the mean HSA score of the adolescents receiving oral chelation therapy was slightly higher than those receiving subcutaneous or subcutaneous and oral chelation therapy, but this difference was not statistically significant(Table 4).

Table 4. HSA mean scores of the adolescents with thalassemia major by diagnosis and treatment characteristics (n=112)

Diagnosis and treatment characteristics	n	HSA Score Mean ± SD	$t/x^2_{KW}/U/Z$, / p value
Having a relative with TM			
Yes	43	1782.5 ± 283.1	t=0.360
No	69	1762.1 ± 296.7	p=0.720
Losing someone to thalassemia			
Yes	5	2014.4 ± 322.2	U =123.500
No	107	1758.5 ± 285.5	Z =[-2.029]
			p=0.042*
Frequency of blood transfusions			
Once every two weeks	9	1990.7 ± 243.7	x^2_{KW} = 4.881
Once every three weeks	91	1748.5 ± 283.2	p=0.087
Once every four weeks	12	1767.4 ± 329.0	
Method of chelation therapy			
Oral route	98	1773.6 ± 296.8	U = 626.500
Subcutaneously/subcutaneously and orally	14	1744.6 ± 249.8	Z = [-0.523] p = 0.601
Presence of other chronic disease			
Yes	9	1711.4 ± 346.4	U = 426.000
No	103	1775.1 ± 286.5	Z = [-0.401] p = 0.688

*p<0.05, **t: Student's t-test, x^2 :Chi-square test, KW: Kruskall Wallis test, U/Z: Mann Whitney U test/Z value.**

The factors related to the HSA scores of the adolescents with TM

Using linear regression analysis, an attempt was made to discover if the father's educational status, the mother's educational status, the losses suffered in the family due to thalassemia, and the frequency of blood transfusions had any effect on mean HSA scores (Table 5).

Table 5. Factors related to the hopefulness scores of the adolescents with thalassemia major (n=112)

Factors[§]	β[†]	SE[‡]	t	p	95% Confidence Interval (CI)	
					Lower	Upper
(Constant)	1894.53	73.23	25.87	0.000	1749.36	2039.71
Mother is an elementary/middle school graduate **(1)** [§]	-9.576	85.55	-0.112	0.911	-179.18	160.032
Father is an elementary/middle school graduate **(1)** [§]	-184.11	70.79	-2.601	0.011*	-324.45	-43.77
Losing a relative to thalassemia **(1)** [§]	239.16	125.47	1.906	0.059	-9.566	487.90
Receiving blood transfusions once every two weeks **(1)** [§]	178.22	96.75	1.842	0.068	-13.57	370.02

* $p < 0.05$.

[†]β: Beta, [‡]SE: Standard Error, [§]Dummy Coding: 1=Yes, 0=No (Model=1, Method=Enter, R=0.388, R^2 =0.151, Adjusted R^2=0.119).

It was found that, after controlling for the other factors, the father's educational status impacted the hopefulness score of adolescents with TM and the educational status of a father with an elementary/middle school education had an adverse effect on the hopefulness score (t = 2.601, p=0.011).

DISCUSSION

As a result of this study, although the hopeful score averages of healthy adolescents were higher than the hopeful score averages of thalassemia major adolescents, this numerical difference was not statistically significant ($p>0.05$; Graph 1). Adolescents with TM may feel less hopeful due to problems encountered in the course of their illness, which include anxiety about the future, body image issues, feelings of difference, delayed growth, complication-related stress, and psychiatric disorders (11,12,13,17,23). In their study, Tajvidi and Zeighami (2012) reported that 59% of adolescents with TM displayed low levels of hopelessness. Pourmovahed et al. (2003) did not find significant differences between the hope levels of adolescents with TM and healthy peers (25). In our sample, the hopefulness scores of the adolescents with TM were similar to those of their healthy peers. This might be explained by the positive impact provided by adequate social support received by the adolescents with TM from their families and especially by the fact that they shared their experiences with peers who suffered from the same illness. Furthermore, developments in the treatment of TM in recent years may have been instrumental in providing families, and consequently their adolescent children with TM, with greater hope about the future.

In our study, however, there were no differences between mean HSA scores according to the gender, age, family type, number of siblings, perceived income status, parents' age, and the employment status or educational level of mothers of adolescents with TM. It was only found that the hopefulness scores of adolescents with TM whose fathers were elementary/middle school graduates were lower than the scores of those whose fathers had higher educational backgrounds. After controlling other factors (the mother's educational status, losses suffered by the family due to thalassemia, and frequency of blood transfusions),

low educational levels of fathers was identified as a factor that adversely affected hopefulness scores. It is fair to state that as parents' educational level rises, they teach their children more and form closer social relationships with them, adolescents' awareness of their diseases increases, adolescents become stronger, and their hopefulness scores are affected as their adaptation to diseases and treatments increases. Esenay and Conk (2007) found a significant relationship between parents' educational level and adolescents' hopefulness scores(26).

In this study, the mean of the adolescents with or without HSA family members is differentiated between HSA scores. Surprisingly, however, thalassemia close relatives had higher hopeful scores than adolescents. Contrary to this finding, those who are familiar with the loss of a close family hotel or a similar illness may have feelings of despair about life and the future. The hopefulness scores of the participating adolescents with TM who used an oral chelator were higher than those who used an oral or subcutaneous chelator, and this difference was not statistically significant. With the recent developments in TM diagnosis and treatment, deferasirox (DFX) oral iron chelator treatments are much easier to administer than desferrioxamine (DFO) parenteral treatments, and DFX oral iron chelator treatments reduce pain and dependence-related feelings. Thus, oral chelators are stated to satisfy patients (29). Adolescents with TM adapted to DFX treatment much better while making an effort not to disrupt iron chelation, which positively affected patients' quality of life and hopefulness scores.

Thalassemia major, starting particularly in adolescence, may lead to serious complications, morbidity, and even mortality (4,7,30). Regular blood transfusions, close monitoring of iron loading, and appropriate iron chelation therapy, which have been the standard course of treatment in recent years, have reduced complication-related adverse

outcomes and changed the prognosis for the illness toward the positive (4, 6). It is also possible to see that because of the complications that accompany this disease, patient complaints and hospital stays may increase, and quality of life and expectations of life may fall (3, 9). Uz et al. (2013) found that 44.4% of patients with TM had accompanying chronic illnesses (diabetes mellitus, coronary artery disease, heart failure, hypophyseal deficiency, and osteoporosis) and that these patients displayed significantly lower scores on the quality of life subscale than patients who did not have concomitant chronic illnesses (9). An increase in the number of concomitant chronic diseases may cause hopefulness scores to decline because of anxiety about the future and a continually diminishing quality of life. There were no differences in our study between the hopefulness scores of adolescents with TM who had or did not have concomitant chronic illnesses. Of the nine adolescents who reported a chronic illness, one indicated heart failure, two reported Type 1 diabetes mellitus, one complained of kidney failure, two of bronchial asthma, and three of osteoporosis and vision impairment. Difficulties in peer relationships and the affective domain may emerge in adolescence when peers' presence and their approval are at the forefront of one's considerations. Complications such as dysmorphosis arising from TM, delayed puberty, and bone deformities may cause adverse body perception and stigmatization, which may distort social functioning and affect adolescents' hopefulness. Adanır et al. (2017) stated that adolescents with beta thalassemia developed related complications, and had difficulties in social, affective, and behavioral functioning while experiencing more issues and difficulties in peer relationships and the affective domain than their healthy peers (31).

Pediatric nurses should determine the hopefulness level of adolescents with TM, identify desperate adolescents' intrinsic (autonomy, independence, logic, cognitive thinking,

etc.) and extrinsic (significant people, healthcare crew, support groups, etc.) sources of hope (relationships, beliefs, etc.), plan nursing practices for raising their hopefulness levels, combine the medical treatment of TM and similar chronic diseases with psychosocial support, and provide holistic nursing care to patients and their families.

Limitations

There are some limitations to this study. First, a random sampling method was not chosen in this study. No homogeneity was found among thalassemic and healthy adolescents in terms of sociodemographic characteristics such as number of siblings, family type, and income level. This may have affected the generalizability of the findings. Second, although the intention was to have the adolescents fill out the HSA themselves, because some struggled to understand some of the questions, the researcher chose to explain the questions before the forms were completed. This may bring a bias risk, but it may also be expected that this risk was diminished as the data were collected by the first researcher alone. Third, since no other studies have been applied the HSA to adolescents with TM, the discussion was carried out on the basis of studies that used the Beck Hopelessness Scale or worked with adolescents who suffered from other chronic diseases. Despite these limitations, however, this study contributes to the literature by shedding light on the hopefulness levels of Turkish adolescents with TM and the factors which affect them.

Since knowledge on this area is limited, it may be said that there is a need for more research to compare the characteristics of diagnosis and treatment of adolescents with TM and their hopefulness.

CONCLUSION

No difference was found between the hopefulness levels of adolescents with TM and those of healthy adolescents. There were differences between the hopefulness levels of adolescents with TM in terms of their fathers' educational background, however. In this context, it was found that the hopefulness levels of adolescents whose fathers were elementary/middle school graduates were lower than those of adolescents whose fathers were high school/university graduates. Other sociodemographic characteristics – having a family member or close relative with TM, frequency of blood transfusions, method of chelation therapy, or the existence of chronic illnesses accompanying TM presented no differences in hopefulness levels.

Nurses should identify the sources that bring hope to adolescents with TM who harbor feelings of hopelessness, and plan interventions that will increase their hopefulness, providing social support to the adolescent and their family to help them cope with the emotional tensions and difficulties that such a chronic illness brings.

REFERENCES

1. Sayani FA, Kwiatkowski JL. Increasing prevalence of thalassemia in America: Implications for primary care. Annals of Medicine 2015; 47(7), 592-604.
2. Vosper J, Evangeli M, Porter JB, Shah F. Psychological factors associated with episodic chelation adherence in thalassemia. Hemoglobin 2018, 42(1), 30-36.
3. Ağaoğlu, L. Talasemi ile yaşam (Life with Thalassemia). Türkiye Klinikleri Journal Hem Onc-Special Topics 2010; *3*(1), 9-13.
4. Cao A, Galanello R. Beta-thalassemia. Genetics in Medicine 201; 12(2), 61-76.
5. Topal Y, Topal H, Ceyhan MN, Azık MF, & Kocabaş CN. Beta Talasemi ile Mücadelede Muğla Deneyimleri (Struggling with Beta Thalassemia: Cases from Muğla), Turkish Journal of Pediatric Disease 2015; 9 (3), 226-229.

6. Aydınok Y. Iron chelation therapy as a modality of management. Hematology/Oncology Clinics of North America. 2018; 32: 261-275.
7. Fortin PM, Fisher SA, Madgwick KV, Trivella M, Hopewell S, Doree C, et. al. Interventions for improving adherence to iron chelation therapy in people with sickle cell disease or thalassaemia. Cochrane Database of Systematic Reviews 2018; Issue 5. Art. No.: CD012349.
8. Aydınok Y. Thalassemia. Hematology 2012; 17(1), 28-31.
9. Uz B, Ongun M, Eliaçık E, Işık A, Aksu S, Büyükaşık Y, ve ark. Beta talasemi major hastalarında yaşam kalitesinin KF-36 ölçeği ile değerlendirilmesi: Tek merkez çalışması, Measuring quality of life with the KF-36 scale in patients with beta thalassemia: a single-site study. Yeni Tıp Dergisi 2013; 30 (2), 70-74.
10. Marcon A, Motta I, Taher AT, Cappellini MD. Clinical complications and their management. Hematology/Oncology Clinics of North America 2018; 32(2), 223-236.
11. Ghanizadeh A, Khajavian S, Ashkani H. Prevalence of psychiatric disorders, depression, and suicidal behavior in child and adolescent with thalassemia major. Journal of Pediatric Hematology/Oncology 2006; 28(12), 781-784.
12. Moorjani JD, Issac C. Neurotic manifestations in adolescents with thalassemia major. Indian Journal of Pediatrics 2006; 73(7), 603-607.
13. Çelebi Kaya B. Beta-talasemi major hastalarında psikiyatrik komorbidite sıklığı ve psikiyatrik bozuklukların yaşam kalitesi ile ilişkisi. Uzmanlık Tezi, Bakırköy Ord. Prof. Mazhar Osman Ruh Sağlığı ve Sinir Hastalıkları Eğitim ve Araştırma Hastanesi, İstanbul, 2009.
14. Shaligram D, Girimaji SC, Chaturvedi SK. Psychological problems and quality of life in children with thalassemia. Indian Journal of Pediatrics 2007; 74(8), 727-730.
15. Gharaibeh HF, Gharaibeh MK. Factors influencing health-related quality of life of thalassemic Jordanian children. Child: Care, Health and Development 2012; 38(2), 211-218.
16. Gollo G, Savioli G, Balocco M, Venturino C, Boeri E, Costantini M, Forni GL. Changes in the quality of life of people with thalassemia major between 2001 and 2009. Patient Preference and Adherence 201; 7, 231-236.

17. Behdani F, Badiee Z, Hebrani P, Moharreri F, Badiee AH, Hajivosugh N, et.al. Psychological aspects in children and adolescents with major thalassemia: a case-control study. Iranian Journal of Pediatrics 2015; 25(3), 322.
18. Lee YL, Lin DT, Tsai SF. Disease knowledge and treatment adherence among patients with thalassemia major and their mothers in Taiwan. Journal of Clinical Nursing 2008; 18(4), 529-538.
19. Saini A, Chandra J, Goswami U, Singh V, Dutta AK. Case control study of psychosocial morbidity in β thalassemia major. The Journal of Pediatrics 2007; 150(5): 516-520.
20. Shaligram D, Girimaji SC, Chaturvedi SK. Psychological problems and quality of life in children with thalassemia. Indian Journal of Pediatrics 2007; 74(8), 727-730.
21. Gharaibeh H, Amarneh BH, Zamzam SZ. The psychological burden of patients with beta thalassemia major in Syria. Pediatrics International 2009, 51(5), 630-636.
22. Hashemi A, Banaei-Boroujeni S, Kokab N. Prevalence of major depressive and anxiety disorders in hemophilic and major beta thalassemic patients. Iranian Journal of Pediatric Hematology Oncology 2012; l2(1), 11-16.
23. Adib-Hajbaghery M, Ahmadi M, Poormansouri S. Health related quality of life, depression, anxiety and stress in patients with beta-thalassemia major. Iranian Journal of Pediatric Hematology Oncology 2015; 5(4),193-205.
24. Tajvidi M, Zeighami MS. The level of loneliness, hopelessness and self-esteem in major thalassemia adolescents. Scientific Journal of Iran Blood Transfus Organ 2012; 9(1), 36-43.
25. Pourmovahed Z, Dehghani KH, Yasini ASM. Evaluation of hopelessness and anxiety in young patients with thalassemia major. Journal of Medical Research 2003; 2(1), 45-52.
26. Esenay FI, Conk Z. Sağlıklı ve kanserli ergenlerde umut. Doktora Tezi. Ege Üniversitesi Sağlık Bilimleri Enstitüsü, İzmir, Türkiye. 2007.
27. Hinds PS, Gattuso JS. Measuring hopefulness in adolescents. *Journal of* Pediatric Oncology Nursing 1991; 8(2), 92-94.
28. Cantrell MA, Lupinacci PA. Predictive model of hopefulness for adolescents. Journal of Adolescent Health 2004; 35, 478-485.

29. Aydınok Y, Erermis Bukuşoğlu N, Yılmaz D, Solak U. Psychosocial implications of thalassemia major. Pediatrics International 2005; 47(1): 84-89.
30. Gharaibeh H, Barqawi MA, Al-Awamreh K, Al Bashtawy M. Clinical burdens of β-thalassemia major in affected children. Journal of Pediatric Hematology/Oncology 2018; 40(3), 182-187.
31. Adanır SA, Taşkıran G, Koparan C, Özatalay E. Beta Talasemili ergenlerde sosyal, duygusal ve davranışsal güçlüklerin ve ebeveynlerinde psikopatolojinin değerlendirilmesi**.** JCP 2017; 15 (3), 35-46.