Life Satisfaction in children and adolescents with beta thalassemia major in southwest Iran

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Abstract:
Background: Beta thalassemia major has a considerable impact on quality of life. The purpose of this study was to determine the life satisfaction of beta-thalassemic children and adolescents compared to healthy controls.
Methods: This research, conducted in 2009, was a controlled, cross-sectional study in which beta-thalassemic patients, who were being followed-up by the Thalassemic Center in Bushehr, a city in southern Iran, were compared with a healthy control group. The Multi-dimensional Student Life Satisfaction Scale (MSLSS) was used to measure the participants' quality of life in five domains. The chi-squared test, t-test, Pearson's Product Moment Correlation, and multiple regression analysis were used for the statistical analyses.
Results: The unadjusted mean scores of three of the domains, i.e., school, friends, and living environment, and the total score of five domains, i.e., school, friends, living environment, family, and self, were significantly higher in thalassemic patients than in the control group ($P < 0.05$). These significant differences were persistent after adjusting the mean scores of the three domains and the total score of the five domains for age, gender, and educational level.
Conclusion: The thalassemic patients were more satisfied with life than the healthy controls in Bushehr. Many factors may be responsible for this finding. The results of this study suggest that the attitude of parents and society concerning assigning responsibility to patients should be assessed. The assessment should include comparing the satisfaction with life of thalassemic patients with that of their healthy siblings and conducting national studies on the quality of life of thalassemic patients and their satisfaction with life.

Keywords: β-thalassemia; multi-dimensional student life satisfaction scale (MSLSS); personal satisfaction; quality of life

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1. Introduction

Thalassemia is a genetic blood disorder characterized by partial or no production of alpha or beta globin chains, which can be fatal if proper treatment is not received (1). The more severe form is beta-thalassemia major, which warrants regular blood transfusions at an early age (2). If left untreated, the result can be early death. For those children who do survive, this condition has serious implications for their health related quality of life (HRQoL) (1), and they have to be treated at the Thalassemia Treatment Center (TTC), which sometimes takes half a day. They also have to undergo iron chelating therapy to remove excess iron from their blood.

Beta thalassemia is an increasingly serious public health problem throughout the Mediterranean region, the Middle East, the Indian subcontinent, and Southeast Asia (1). Beta thalassemia has been a major public health problem in

Iran for many years. Fortunately, obligatory blood tests at the time of marriage have been required by governmental health center since 1995, which has had a significant impact on controlling the incidence of beta thalassemia major. Also, in recent years, religious and governmental authorities have permitted therapeutic abortions before 16 weeks of gestation after prenatal diagnosis of beta thalassemia. Even so, the Charity Foundation for Special Diseases (CFFSD) reported that there are about 15,000 thalassemic patients in Iran, mainly as a result of the years when there were no control programs and when they were just being established (3).

Morbidity and mortality related to thalassemia have been reduced significantly with modern medical treatment, and the quality of life (QoL) should now be considered as an important index of effective healthcare. A study of adults with thalassemia indicated that treatment and cultural differences had no major effect on QoL in Cypriot patients with thalassemia (4). Another study of children compared the QoL of patients with thalassemia intermedia to that of patients with thalassemia major and found that transfusion–independent thalassemia patients also suffer impairments in their QoL (5). The assessment of QoL differs from other forms of medical assessments of other aspects of life, giving a more holistic view of the patient's well-being (4). There has been very limited research about the effects of thalassemia on QoL, especially for pediatric patients (1, 2, 6-9), and such studies are especially scarce in Iran (10). Fortunately, in recent years, many more studies have been conducted in Iran concerning the QoL of beta-thalassemic patients using various methods and questionnaires (11-14). Unfortunately, there have no QoL and life-satisfaction studies for beta-thalassemia patients in Bushehr.

The MSLSS was developed and validated by Scott Huebner in 1994 (15), and it continues to be one of the most comprehensive, subjective scales in the area of childhood well-being. The MSLSS assesses children's subjective perception of life satisfaction (LS) in five domains, i.e., family, friends, school, self, and living environment (16). In recent years, many studies have been conducted in several English-speaking countries around the world in which different versions of the MSLSS have been used to evaluate healthy and diseased children and adolescents (17-23). Also, the assessment tool has been translated into other languages, including Turkish and Persian. One study provided clues concerning the validity and reliability of the Persian adaptation of the MSLSS in healthy students of ages 12-18 in Iran (24, 25). The aim of this study was to compare the life satisfaction of beta-thalassemic children and adolescents with healthy (non-thalassemic) controls in the five domains of MSLSS.

2. Material and Methods

In a controlled, cross-sectional study in 2009, 100 patients with beta thalassemia were assessed during their follow-up visits with the TTC in the Department of Pediatrics at the Ali-e-Asghar Pediatric Center at the Bushehr University of Medical Sciences. The inclusion criteria were all children and adolescent patients in secondary and high school who gave informed consent. Life satisfaction was measured using the self-administered MSLSS (15) that had been translated into Persian and validated (24). The control group consisted of students in grades 6-12 in secondary schools and high schools in Bushehr, and these students were selected using systematic random sampling. The members of the control group were matched with thalassemic patients based on their comparable educational levels.

The Persian adaptation of the MSLSS was administered and completed by the thalassemic patients and the members of the control group. All students were briefed by their teachers concerning the purpose of the investigation and asked to participate in the study. Students who agreed to participate were directed to read and sign an informed consent form. The students also were given a consent form for their parents to complete. The procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation in the Bushehr University of Medical Sciences.

The present version of the MSLSS contains 40 items. Students were asked to answer the items by marking one response on the six-point Likert scale. The score of each domain was the sum of the scores of all of its items. The total score was the sum of the scores of the five domains. The MSLSS was free, and the English version is available on the website of the University of South Carolina (26). The chi-squares test, t-test, Pearson's Product Moment Correlation, and multiple regression analyses were performed by using the Statistical Package for Social Science 11.0 (SPSS, Inc., Chicago, IL, USA). Alpha = 0.05 was set as the level of significance in the statistical analyses. Descriptive results also were presented in the form of proportions, means, and standard deviations.

3. Results

A total of 89 of the 100 patients who received treatment at the TTC participated and completed the questionnaire (response rate = 89%). Also, 100 healthy students in the control group completed the questionnaire. The mean ages of the thalassemic patients and the healthy students who served as controls were14.84 ± 3.22 and 14.46 ± 2.1, respectively. Fifty-five (61.8%) of the thalassemic patients were males, and 56 (62.9%) of the thalassemic patients were in secondary school. For the 100 healthy controls, 51 (51%) were males, and 60 (60%) were in secondary school. Table 1 summarizes the demographic characteristics of the 89 beta-thalassemic patients and the 100 healthy controls. The two groups did not have any significant differences regarding age, gender, or educational level (P > 0.05).

Table 1. Demographic characteristics of thalassemic patients and healthy controls

	Thalassemia Patients [a] (n= 89)	Healthy controls [a] (n= 100)	P value
Age	14.84 (3.22)	14.46 (2.1)	0.34
Gender			
Female	34 (38.2)	49 (49)	0.08
Male	55 (61.8)	51 (51)	
Educational level			
Secondary	56 (62.9)	60 (60)	0.76
High	33 (37.1)	40 (40)	

[a] Expressed as mean and standard deviation

Table 2. Scores of the MSLSS' five domains in thalassemic patients and healthy controls

Domains	Thalassemia Patients [a] (n=89)	Healthy Control [a] (n=100)	P value
Family	23.69 (4.49)	23.64 (3.48)	0.93
Self	20.87 (4.72)	21.44 (4.4)	0.38
Living Environment	25.02 (5.77)	23.29 (4.99)	0.028 †
Friends	29.31 (5.58)	27.12 (5.17)	0.006 †
School	26.3 (5.12)	23.13 (4.83)	0.000 1†
Total	125.19 (18.4)	118.62 (15.35)	0.008 †

[a] Expressed as mean and standard deviation

Table 3. Difference in the LS scores of five domains and the total score between thalassemic children and healthy controls after adjustments for age, gender, and educational level

Domains	Regression Coefficient	95% CI	P value	Adjusted R^2
Family	0.98	0.91 to 1.05	0.63	0.03
Self	1.02	0.95 to 1.08	0.54	0.034
Living Environment	0.92	0.87 to 0.98	0.009†	0.068
Friends	0.91	0.86 to 0.97	0.003†	0.08
School	0.85	0.8 to 0.91	0.0001†	0.14
Total	0.97	0.95 to 0.98	0.002†	0.085

Table 2 lists the unadjusted mean scores on the MSLSS for the five domains and the total scores for the thalassemic patients and the healthy controls. The scores of three domains (living environment, friends, and school) and the total score were significantly higher for the thalassemic patients than for the healthy controls. In the thalassemic patients, the score for the self domain was lower than that for the healthy controls, but the difference was not significant (P >

0.38). A multiple regression analysis was conducted to adjust the mean score of each of the domains and the total score of the five domains for age, gender, and educational level. The model was statistically significant for all domains, except family and self. Also, it was significant for the total score (Table 3).

4. Discussion

The assessment of LS in children with a chronic illness, such as beta thalassemia, is particularly important. In the present study, the MSLLS was used to assess the LS of thalassemic children in five domains, and the results were compared to LS of their healthy counterparts. The scores for LS were significantly different in the different domains for thalassemic patients and healthy controls, as were the total LS scores for the two groups. The thalassemic children had a better perception of their LS than the controls in the domains of living environment, friends, and school. There were no significant differences between the two groups in the domains of family and self.

Data regarding the effect of chronic disorders on the psychosocial integration of children and adolescents are contradictory. The earlier assumption that a chronic condition predisposes children to psychological maladjustment does not appear to be definitive. The discrepancies among the results could be due to various factors, including the measurements that were used, the responders' perspectives (more likely for the parents than the children), the size of the population studied (larger size more likely), and whether a single disorder or multiple disorders were studied (multiple more likely). Therefore, larger epidemiological studies continue to support the evidence of an increased likelihood of having behavioral, emotional, and social problems, such as being antisocial, anxious/depressed, headstrong, hyperactive, peer conflict/social withdrawal, and immaturity/dependency (27-29).

Most researchers have found that people with chronic diseases have increased risk of developing psychosocial disturbances (1, 11, 12, 30-33); however, other researchers have been unable to confirm these findings (34). Many studies have indicated that thalassemia has a negative effect on QoL of children with this disease in Iran and other countries, but some studies have not shown this effect (35). Thalassemia is a chronic disorder that interferes with the course of everyday life because patients must have daily iron-chelation therapy, mainly by wearing an electronic pump, and they also must go to the treatment center periodically to be transfused. In the past, the disease caused facial deformities that could adversely affect body image and self-esteem. Accordingly, one would expect that subjects with thalassemia would be at increased risk of psychosocial disturbances (35). In fact, Tsiantis found that 42% of thalassemic patients that he followed in Greece had psychiatric problems, even if they had a normal self-concept (30). Aydin reported more hopelessness, more anxiety, and lower self-images in thalassemic patients than in the control group (31).

Ismail et al. compared HRQol in Malaysian thalassemic children in the age range of 5-18 with healthy controls. They concluded that thalassemia has a negative impact on perceived physical, emotional, social, and school functioning in patients and that the impact was worse than that among the healthy counterparts (1). Alavi et al. assessed the QoL of 39 children and adolescents with thalassemia major in Shahr-e-Kord, Iran, using the Pediatric Quality of Life Inventory TM (PedsQL). They reported a significant difference between QoL reported by patients and parents. Although there were no differences in social and school domains, the differences in the physical and emotional domains were significant (11).

Malekshahi's study of thalassemic patients in KhoramAbad, Iran, showed that the patients had different emotional problems (32). Khani et al. conducted a study on the assessment of QoL of thallasemic patients aged 15 years old or more using Short Form 36 (SF-36), Symptom Checklist-90-Revised (SCL-90-R), and Life Satisfaction Inventory (LSI) questionnaires in Iran at the south coast of the Caspian Sea. They concluded that the patients were vulnerable to different psychiatric problems and recommended psychological consultation (12). Azarkeivan et al., in a cross-sectional study that was conducted in an outpatient, adult thalassemia clinic, i.e., the Blood Transfusion Organization in Tehran, Iran, used SF-36 for measuring HRQoL in 179 patients with beta thalassemia (major/intermedia). They concluded that depression is associated with both poor physical and mental HRQoL among patients; however somatic comorbidities and anxiety were associated with poor physical and mental HRQoL, respectively (33).

Parallel research studies were conducted in Athens and Ferrara, and another investigation that was conducted in Ferrara did not confirm this. They showed that adolescents and young adults with thalassemia have psychosocial development that is comparable to that of subjects of the same age group without thalassemia. Another investigation conducted in Ferrara demonstrated that subjects with thalassemia also may have a normal marital life (35). It is not possible to say with certainty why the psychosocial adjustment of subjects with thalassemia in Athens, Ferrara, and

Bushehr was quite good in spite of the disease. Tsiantis et al. (36) found that thalassemia has a uniting effect on the family, contrary to what was expected.
In accordance with Tsiantis' comment, we observed during our daily medical visits with the thalassemic patients and by accompanying their family members in the TTC that the families coped quite well with the disease and ignored the patients' issues in daily life more than they did for their other children who were healthy. In other words, perhaps the family makes sacrifices for them because they are sick. Seid Fatemi et al. (37), in their study of the parents of thalassemic children, found that 54% of the parents used moral support as the coping style.

Vardaki et al. (38), in a survey of adults suffering from beta thalassemia major and receiving treatment on the Island of Crete, extracted the factors that were associated with their attitudes and expectations. An indicator on optimism was associated with a positive comparative assessment of health status, while an indicator on adaptability was associated with a positive subjective assessment of health status. This indicator also was higher in those satisfied with the services, but it was lower in the best-educated group. An indicator on pessimism was associated with a negative comparative assessment of health status and with the lowest level of education. A study indicated that the quality of life in adult patients with congenital heart disease was better than that of their healthy counterparts. A possible explanation for this is that these patients have a stronger sense of coherence than their healthy counterparts. Moons et al. (39) advanced the hypothesis that, in children with chronic diseases, the enhanced sense of coherence (SOC) develops in childhood through the successful application of generalized resistance resources, and it may be a potential pathway for improving the quality of life in patients who grow up with a chronic health condition. Also, Brantley et al. (22) used the MSLSS to compare the life-satisfaction reports of 80 high school students with mild mental disabilities with those of a matched sample of 80 typically-achieving students. Comparisons of mean levels of general and domain-specific satisfaction suggested that the students with mild mental disabilities reported comparable positive levels with two exceptions. They reported lower satisfaction with their friendships and higher satisfaction with school experiences than did their typically-achieving counterparts.

Wolman et al. (40) investigated whether adolescents with chronic conditions differ from adolescents without chronic conditions in several psychological outcomes. He concluded that, although adolescents with chronic conditions do not do as well as adolescents without chronic conditions, having a disability is not the most influential factor on emotional well-being. Family connectedness is of fundamental importance for adolescents' emotional health. Also, it must be considered that their standards of comparison and their level of aspirations may be lower, so they are more satisfied with less achievement. It can be argued that the management of chronic illnesses should be family-oriented and should not just deal with the management of the physical aspects of the illness. The professional team (pediatricians, nurses, mental health professionals) should ensure that, at the least, all family members should be made aware of the nature of the illness, the care it entails, and the likely associations of physical and psychosocial aspects. The family's coping and adapting mechanisms should be acknowledged and seen in the light of the family's attempt to achieve equilibrium rather than comparing them rather negatively against 'normal' families. Such coping mechanisms should be encouraged and fostered as long as they do not become pathological. The support of social structures and agencies should be made available, when necessary (41).

When children have special healthcare needs, parents assume the roles of care coordinator, medical expert, and systems advocate in addition to their typical parenting roles. They face many challenges in managing their child's chronic condition in the context of everyday life. Healthcare providers are uniquely positioned to assist parents in meeting those challenges and to promote parents' competency and confidence in the care of their children (42).
Considering the limitations of this study, it should be noted that the study was conducted only in one center and one province. So, our results could not be representative of all thalassemic patients in Iran. National studies involving a more representative sample of all thalassemic patients in Iran could help to assess their LS more accurately.

5. Conclusions

In this study, we assessed LS in five domains, concentrating on the positive indicators of well-being in children and adolescents. This was in contrast to many other studies in Iran and other countries that have focused on negative indicators, such as anxiety and depression. It seems that family members, teachers, friends, and classmates treat thalassemic patients differently than healthy children and adolescents. The importance of these findings is that using this Persian adaptation of the MSLSS may help to assess LS in patients with beta thalassemia and other chronic diseases in order to identify different domains responsible for their problems so appropriate interventions can be planned and used. The reasons for this better satisfaction could be investigated in three aspects, including patients, the public, and medical staffs in future studies, especially qualitative studies such as focus group discussions

(FGDs). Also, we suggest that a measure be designed to assess the attitude of parents and society concerning assigning responsibility to these patients. Comparing the LS of thalassemic patients with that of their healthy siblings could be beneficial.

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Conflict of Interest:
There is no conflict of interest to be declared.

Authors' contributions:
Both authors contributed to this project and article equally. All authors read and approved the final manuscript.

References

1. Ismail A, Campbell MJ, Hishamshah M I, Jones GL. Health Related Quality of Life in Malaysian children with thalassaemia. Health Qual Life Outcomes. 2006;4:39-46. Pubmed PMID: 16813662.
2. Dahlui M, Hishamshah MI, Rahman AJ, Aljunid SM. Quality of life in transfusion-dependent thalassaemia patients on desferrioxamine treatment. Singapore Med J. 2009;50:794-9. Pubmed PMID: 19710979 .
3. Charity Foundation for Special Diseases (CFFSD). Khasse Magazine. 2002;4:45-9. Persian.
4. Telfer P, Constantinidou G, Andreou P, Christou S, Modell B, Angastiniotis M. Quality of life in thalassemia. Ann N Y Acad Sci. 2005;1054: 273-82. Pubmed PMID: 16339675.
5. Pakbaz Z, Treadwell M, Yamashita R, Quirolo K, Foote D, Aura Quill, L, et al. Quality of Life in Patients with Thalassemia Intermedia Compared to Thalassemia Major. Ann N Y Acad Sci. 2005;1054:457-61. Pubmed PMID: 16339697.
6. Abetz L, Baladi J F, Jones P, Rofail D. The impact of iron overload and its treatment on quality of life: results from a literature review. Health Qual Life Outcomes. 2006;4:73-7. Pubmed PMID: 17007645 .
7. Cheuk DK, Mok AS, Lee AC, Chiang AK, Ha SY, Lau YL, et al. Quality of life in patients with transfusion-dependent thalassemia after hematopoietic SCT. Bone Marrow Transplantation. 2008;42:319-27. Pubmed PMID: 18560410.
8. Mikelli A, Tsiantis J. Brief report: Depressive symptoms and quality of life in adolescents with beta-thalassaemia. J Adolesc. 2004;27:213-16. Pubmed PMID: 15023520.
9. Scalone L, Mantovani LG, Krol M, Rofail D, Ravera S, Bisconte MG, et al. Costs, quality of life, treatment satisfaction and compliance in patients with beta-thalassemia major undergoing iron chelation therapy: the ITHACA study. Curr Med Res Opin. 2008;24:1905-17. Pubmed PMID: 18507891.
10. Jafari H, Lahsaeizadeh S, Jafari P, Karimi M. Quality of life in thalassemia major: reliability and validity of the Persian version of the SF-36 questionnaire. J Postgrad Med. 2008;54:273-5. doi: 10.4103/0022-3859.41432. Pubmed PMID: 18953145.
11. Alavi A, Parvin N, Kheiri S, Hamidizadeh S, Tahmasbi S. (2006). [Comparison of the views of thalassemic children with their parents about their quality of life]. Journal of Shahrekord University of Medical Sciences. 2006;8:35-41. Persian
12. Khani H, MajdAbadi MR, AzadMarzAbadi E, Montazeri A, Ramezani M. (2008). [Quality of life in patients with thalassemia major in the south coast of Caspian Sea]. Journal of Behavorial Sciences. 2008;2:325-33. Persian
13. Allahyari A, Alhany F, Kazemnejad A, Izadyar M. [The effect of family-centered empowerment model on the Quality of Life of school-age B-thalassemic children]. Iranian Journal of Pediatrics. 2006;16:455-61. Persian
14. Yousofi AR, Nouri A, Kamkar N. [Assessment of the quality of life of thalassemia major patients and their family in Isfahan, Iran]. Journal of Knowledge and Research in Psychology. 2006;27:149-66. Persian
15. Huebner ES. Preliminary Development and Validation of a Multidimensional Life Satisfaction Scale for Children. Psychological Assessment. 1994;6:149-58 .
16. Greenspoon PJ, Saklofske DH. Confirmatory factor analysis of the multidimensional Students' Life Satisfaction Scale. Pers Individ Dif.1998;25:965-71. doi:10.1016/s0191-8869(98)00115-9.
17. Zullig KJ, Huebner ES, Gilman R, Patton JM, Murray KA. Validation of the brief multidimensional students' life satisfaction scale among college students. Am J Health Behav. 2005;29:206-14. doi: http://dx.doi.org/10.5993/AJHB.29.3.2. Pubmed PMID: 15899684.
18. Seligson JL, Huebner ES, Valois RF. Preliminary validation of the Brief Multidimensional Students' Life Satisfaction Scale (BMSLSS). Social Indicators Research. 2003;61:121-45.
19. Park N, Huebner ES, Laughlin JE, Valois RF, Gilman R. A Cross-cultural Comparison of the Dimensions of Child and Adolescent Life Satisfaction Reports. Social Indicators Research. 2004;66:61-79 .
20. Gilman R, Huebner ES, Laughlin JE. A first study of the Multidimensional Students' Life Satisfaction Scale with adolescents. Social Indicators Research. 2000;52:135-60 .

21. Huebner ES, Gilman R. An introduction to the Multidimensional Students' Life Satisfaction Scale. Social Indicators Research. 2002;60:115-22. doi: 10.1023/A:1021252812882 .
22. Brantley A, Huebner ES, Nagle RJ. Multidimensional life satisfaction reports of adolescents with mild mental disabilities. Mental Retardation. 2002;40:321-29. doi: 10.1352/0047-6765(2002)040<0321:MLSROA>2.0.CO;2. Pubmed PMID: 12123396.
23. Huebner ES, Suldo S, Valois RF, Drane JW, Zullig K. Brief multidimensional students' life satisfaction scale: sex, race, and grade effects for a high school sample. Psychological Reports. 2004;94:351-6. doi: 10.2466/pr0.94.1.351-356 . Pubmed PMID: 15077789.
24. Hatami G, Motamed N, Ashrafzadeh M. Confirmatory factor analysis of Persian adaptation of Multidimensional Students Life Satisfaction Scale (MSLSS). Social Indicators Research. 2010;98:265-71. doi: 10.1007/s11205-009-9538-2.
25. Irmak S, Kuruüzüm A. Turkish Validity Examination of the Multidimensional Students' Life Satisfaction Scale. Social Indicators Research. 2009;92:13-3. doi: 10.1007/s11205-008-9284-x.
26. Huebner S. Manual for the multidimensional students, life satisfaction scale. Department of Psychology, University of South Carolina, Columbia. 2001 [cited 2007 August 20]. Available from: http://www.psych.sc.edu/pdfdocs/huebslssmanual.doc .
27. Wallander JL, Varni JW, Babani L, Banis HT, Wilcox KT. Children with chronic physical disorders: Maternal reports of their psychological adjustment. J Pediatr Psychol. 1998;13:197-212. Pubmed PMID: 3171813.
28. Gortmaker SL, Walker DK, Weitzman M, Sobol AM. Chronic conditions, socioeconomic risks and behavioral problems in children and adolescents. Pediatrics. 1990;85:267-76. Pubmed PMID: 2304779.
29. Cadman D, Boyle M, Szatmari P, OtTord DR. Chronic illness, disability, and mental and social wellbeing: Findings of the Ontario Child Health Study. Pediatrics. 1987;79:805-13. Pubmed PMID: 2952939.
30. Tsiantis J. Family reactions and relationships in Thalassemia. Ann N Y Acad Sci.1990;612:451-61. Pubmed PMID: 2149810.
31. Aydin B, Yaprak I, Akarsu D, Okten N, Ulgen M. Psychosocial aspects and psychiatric disorders in children with thalassemia major. Acta Paediatr Jpn. 1997;39:354-7. Pubmed PMID: 9241900.
32. Malekshahi F, Toolabi T, Ravanshad F. [Assessment of psychiatric and behavorial problems in thalassemic patients referring to Shahid Madani Hospital in Khoramabad, Iran]. Journal of Mental Health Principles. 2001;11-12:115-21. Persian
33. Azarkeivan A, Hajibeigi B, Alavian SM, Moghani Lankarani M, Assari S. Associates of poor physical and mental health-related quality of life in beta thalassemia- major/intermedia. J Res Med Sci. 2009;14:349-55. Pubmed PMID: 21772908. Pubmed Central PMCID: PMC3129078.
34. Kellerman J, Zeltzer L, Ellenberg L, Dash J, Rigler D. Psychological effects of illness in adolescence. I. Anxiety, self-esteem and perception of control. J Pediatr. 1980;97:126–31. doi: 10.1016/S0022-3476(80)80152-1. Pubmed PMID: 6966685.
35. Di Palma A, Vullo C, Zani B, Facchini A. Psychosocial Integration of Adolescents and Young Adults with Thalassemia Major. Ann N Y Acad Sci. 1998;850:355-60. doi: 10.1111/j.1749-6632.1998.tb10493.x. Pubmed PMID: 9668558.
36. Tsiantis J, Dragonas T, Richardson C, Anastasopoulos D, Masera G, Spinetta J. Psychosocial problems and adjustment of children with beta-thalassemia and their families. European Child and Adolescent Psychiatry. 1996; 5: 193-203. doi: 10.1007/BF00538846. Pubmed PMID: 8989558.
37. Seid Fatemi N, Yazdi K, Sari Sorkhabi R, Aghazadeh A. [Mental, social and economical problems and the coping style in thalassemic patients parents]. Journal of Mental Health Principles. 2002;15-16:117-25. Persian
38. Vardaki MA, Philalithis AE, Vlachonikolis I. Factors associated with the attitudes and expectations of patients suffering from beta-thalassaemia: a cross-sectional study. Scand J Caring Sci. 2004;18:177-87. doi: 10.1111/j.1471-6712.2004.00267.x. Pubmed PMID: 15147481.

39. Moons P, Norekval TM. Is sense of coherence a pathway for improving the quality of life of patients who grow up with chronic diseases? A hypothesis. Eur J Cardiovasc Nurs. 2006;5:16-20. doi: 10.1016/j.ejcnurse.2005.10.009. Pubmed PMID: 16298552.
40. Wolman C, Resnick MD, Harris LJ, Blum RW. Emotional well-being among adolescents with and without chronic conditions. J Adolesc Health. 1994;15:199-204. doi: 10.1016/1054-139X(94)90504-5. Pubmed PMID: 8075089.
41. Sein EP. Chronic illness: the child and the family. Current Pediatr. 1999;9:177-81. doi: 10.1016/S0957-5839(99)90093-3.
42. Kratz L, Uding N, Trahms CM, Villareale N, Kieckhefer GM. Managing Childhood Chronic Illness: Parent Perspectives and Implications for Parent-Provider Relationships. Fam Syst Health. 2009;27:303-13. doi: 10.1037/a0018114. Pubmed PMID: 20047354.