# *The Relationship between Family Cohesion and Quality of Life in Patients with beta-thalassemia Major: A Study in Southwestern Iran*

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## ABSTRACT

**Introduction:** Thalassemia is a group of genetic disorders caused by defects in the production of certain hemoglobin chains that beta-thalassemia is the most common recurrent type of this inherited blood disorder. The quality of life of patients with thalassemia is low for several reasons. Considering the effects that family cohesion has on improving the complications of this disease and quality of life and that a limited study has been done in this field and the effect of family cohesion in improving the quality of life of patients with beta-thalassemia major has received less attention, this The aim of this study was to investigate the relationship between family cohesion and quality of life of people with beta-thalassemia major in Iran in Behbahan during 2019.

**Methods:** The present study is a cross-sectional analytical study that aims to investigate the relationship between family cohesion and quality of life of people with beta-thalassemia major in Behbahan, Iran in 2019 on 101 patients with thalassemia major who were admitted to Shahidzadeh Hospital. They had visited Behbahan. Inclusion criteria were: having thalassemia major, having the patient's consent to participate in the study, having full consciousness, having literacy, and having at least one history of hospitalization. Exclusion criteria included incomplete questionnaire completion. Data collection tools included three questionnaires of demographic characteristics, mouse family cohesion (2009), and quality of life SF_36. And the method of data collection was based on self-report and filling out questionnaires. Finally, the obtained data were analyzed using SPSS software version 18 and Chi-square, independent t-test, Pearson correlation coefficient.

**Results:** There was a statistically significant relationship between marriage and quality of life and surgical history and family cohesion ($P < 0.05$). The relationship between other demographic variables and quality of life and family cohesion was not significant ($P > 0.05$). There was no statistically significant correlation between the quality of life and its dimensions and total family cohesion score ($P > 0.05$).

**Conclusion:** The final result of the present study showed that there is no statistically significant correlation between the quality of life and its dimensions and the total score of family cohesion in patients with thalassemia major in Behbahan. Evaluation of indicators and factors related to the quality of life in patients with thalassemia major is an essential first step in optimizing clinical and psychological support.

**Keywords:** Beta-thalassemia, Family Cohesion, Quality of Life.

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## Introduction

Thalassemia is a group of genetic disorders caused by defects in the production of certain hemoglobin chains that are passed from generation to generation according to Mendelian genetic laws.[1,2] Beta thalassemia is the most common recurrent form of this inherited blood disorder.[3,4] About 3% of the world's population carry the beta-thalassemia gene.[5] The disease is more common in the Mediterranean, North Africa, East and West Asian countries such as Greece, Italy, Turkey, Thailand, Indonesia, Saudi Arabia, Pakistan, Afghanistan, and India.[6] It is estimated that about 95% of patients are born in Asia, India and the Middle East, where the average prevalence of thalassemia is about 4%.[5,7] In Iran, thalassemia is the most common genetic disorder.[8] and is more prevalent in the southern provinces and northern coasts.[5] The cost of care treatment for each thalassemia patient is estimated at 35 million Rials per year and for all these patients in the country is estimated at more than 700 billion Rials per year.[9] This disease, which is one of the most important problems in the field of health treatment, is considered a problem of medicine and society today.[10,11] Regular blood and iron chelation transfusions are standard care for thalassemia patients.[3] Frequent blood transfusions improve patients' life expectancy and quality of life but can lead to chronic iron overload.[12] Although new drugs have been able to reduce iron accumulation in the organs of the body and increase survival, many challenges remain, such as endocrine problems, a high percentage of chronic hepatitis C, and psychosocial complications associated with chronic diseases.[13]

Quality of life of patients with thalassemia due to various psychological, physical, economic, and social reasons due to chronic disease, frequent hospital visits for blood transfusion, sexual immaturity, medications, inability to reduce complications related to their disease, infertility, disorders Psychology, employment problems, role-playing in society, and uncertainty about the future are low.[14] Quality of life is a wide range of objective human needs that are achieved in relation to individuals' personal and group perceptions of a sense of well-being.[15]

Patients with thalassemia major face many challenges in their lives, and in dealing with these challenges, the role of their families in providing various types of social support are very important.[16] Babapour said in a study in 2012: "When a family member suffers from a chronic illness, the family is faced with difficult situations and decisions, and relationships between family members may be disturbed. Parents may feel that they have to spend most of their time with the sick child of the family, and on the other hand, the other children of the family feel isolated and neglected".[17] Therefore, it can be concluded that having a child with thalassemia major may disrupt the cohesion and dynamism of the family.[18] Family cohesion is actually the feeling of closeness and emotional connection within the family, which is expressed through the feeling of belonging and acceptance in the family system.[19] In a 1996 study, Feldman found that low cohesion among family members could lead to depression and decreased social acceptance.[20]

Today, with the advances that have been made in the treatment of thalassemia patients, life expectancy in these patients has increased and also more of them live longer.[21] However, according to studies, these patients suffer more from anxiety and depression and quality of life

disorders than healthy people, and this quality-of-life disorder has a negative effect on patient's social life, family, work and leisure activities, and the risk of hospitalization and Increases death from the disease.[22–24] In a study conducted, Madmali and his colleagues Concluded that people with thalassemia equate the disease with feelings of hopelessness and worse health than others, which leads to a decrease in general health and quality of their life.[25] Vafaie and his colleagues in a study after examining the quality of life of patients with thalassemia found that the highest quality in the field of role-playing for physical reasons and the lowest quality in the field of the general health of patients and the quality of care is at a desirable level.[10] During a study, Zare and his colleagues showed that the quality of life of patients and their family members are low regardless of age, gender, family income, and level of education.[9] Arian and his colleagues conducted a study in 2013 that the findings of this study show that patients with thalassemia major are prone to a variety of physical and mental problems and as a result a significant reduction in all aspects of quality of life.[26] In a study, Canatan and his colleagues reported 60% of academic difficulty, 20% of social interaction, 24% of feeling different, and 31% of anxiety in children with thalassemia.[27] In their study, Aydinok and his colleagues Found that teenagers with thalassemia major had more depression and lower quality of life than patients with short-term injuries. However, the severity of depression was milder in older teenagers and girls had higher quality of life and milder depression than boys in both groups, which was not statistically significant.[28]

Finally, with a brief summary of the studies, it can be seen that thalassemia major has many complications and psychosocial and physical effects on the patient and parents, and other family members and these complications can affect their quality of life in various dimensions. Therefore, identifying the quality of life of patients and their parents leads to a better understanding of their specific needs and the use of a more effective care-treatment plan. Also, considering the effects that family cohesion has on improving the complications of this disease and quality of life and that in this field, a limited study has been done and the effect of family cohesion in improving the quality of life of patients with Beta-thalassemia major has received less attention. The aim of this study was to investigate the relationship between family cohesion and quality of life in patients with Beta-thalassemia major in Iran in Behbahan during 2019.

## Method

The present study is a cross-sectional analytical study that aimed to investigate the relationship between family cohesion and quality of life of people with Beta thalassemia major in Behbahan City in Iran in 2019 on 101 patients with thalassemia major who were referred to Behbahan Shahidzadeh Hospital. During the study, the researchers were bound to keep patients' secrets and research ethics in accordance with the principles of Helsinki, and before entering the study, all patients were informed.

Inclusion criteria were: having thalassemia major, having the patient's consent to participate in the study, having full consciousness, having literacy, and having at least one history of hospitalization. Exclusion criteria included incomplete questionnaire completion.

Subjects were selected by purposive sampling method and data collection tools included three questionnaires of demographic characteristics, mouse family cohesion (2009), and quality of life SF_36. And the method of data collection was based on self-report and filling out questionnaires.

Demographic characteristics questionnaire included age, sex, body mass index, ethnicity, education, occupation, marital status, monthly

income, hospitalization history, and medications used.

To evaluate the family cohesion, the mouse questionnaire (2009) which has 9 questions was used. Its score range is in two scales: completely correct (0) and completely false (1). The inverted items of this questionnaire are items 1, 3, 4,6, 8, 9. The answers are added to make the total score of the people. The higher the score, the greater the cohesion and cohesion in the family environment. The minimum score is zero and the maximum score is 9, which is a score between 0 and 3, low cohesion and family cohesion, a score between 3 to 5, average cohesion and family cohesion, and a score Above 5 indicates a high degree of family cohesion and cohesion. In terms of reliability and correlation, the researcher obtained the validity of this questionnaire by0.86 and the internal consistency of the questionnaire by 0.78.[29]

The SF-36 questionnaire was used to assess the quality of life of patients, which includes 36 questions. The questions of this questionnaire include 8 concepts that include: areas of physical function, social functioning, role dysfunction due to physical health, pain, general health, role disorder for emotional health, fatigue energy, and general health. The scores for each question were at least zero and at most 100. 2-choice questions with scores (50, 100), 3-choice questions with scores (0, 50, 100) 5-choice questions with scores (0, 25, 50, 75, 100), 6-choice questions with scores (0, 20, 40, 60, 80, 100) were considered. A person's physical health score of the average total dimensions of physical function, role disorder due to physical health, door, and general health is calculated. The mental health score of these patients is obtained from the average total dimensions of role disorder due to emotional health, fatigue energy, emotional well-being, and social function. Taking the total quality of life score of the people, the average of all the dimensions studied is calculated. The average of each domain is calculated for each individual and if this average is less than 50, the quality of the respective domain is low. And if it is more than 50, the quality of the relevant area will be considered high. The SF_36 Quality of Life Questionnaire is a standard criterion for use in health policy assessment, health and general health status assessment, and in research and clinical practice. The reliability of this test in 1992 in the UK was determined by Brazier and his colleagues Based on the Cronbach's alpha test, above 85%.[30] Montazeri and his colleagues in Iran in a study aimed at translating, determining the validity and reliability of the Persian version of the SF_36 questionnaire showed that except for the vitality scale ($\alpha$ = 0.65) other Persian species scales SF_36 of the minimum standard reliability coefficients in the range of 0.77 to 0.9.[31]

After the initial selection of the sample and obtaining their satisfaction, the researchers provided them with the SF_36 quality of life questionnaire. The subject was fully explained to patients and controls. The control group was randomly selected from the patients' participants referred to the general clinic next toBehbahan Shahidzadeh Hospital. Finally, the data were analyzed using SPSS version 18 statistical test, Chi-square tests, Pearson correlation.

## Results

The sample consisted of 101 patients with Beta-thalassemia major with a mean age of 24.21±5.4 Of these, 52.5% were male and the rest were female and 76.23% were single and the rest were married. **Table 1** shows the demographic information of these people.

There was a statistically significant relationship between marriage and quality of life and surgical history and family cohesion (P <0.05).

The relationship between other demographic variables and quality of life and family cohesion was not significant (P >0.05)(**Table 1**).

The mean total score of family cohesion was 4.63±1.81 which indicated the average level of family cohesion and cohesion in these subscales.

| Relation with Family cohesion p value | Relation with quality of life p value | Percent (%) | N | Categories | Item |
|---|---|---|---|---|---|
| 0.44 | 0.64 | 52.5 | 53 | Male | Sex |
| | | 47.5 | 48 | Female | |
| 0.10 | *0.02 | 76.23 | 77 | Single | Marital status |
| | | 23.77 | 26 | Married | |
| 0.95 | 0.24 | 58.41 | 59 | Urban | Place of residence |
| | | 41.6 | 42 | Rural | |
| 0.58 | 0.27 | 3.9 | 4 | Illiterate | Level of education |
| | | 48.6 | 49 | Under diploma | |
| | | 29.8 | 30 | Diploma | |
| | | 5.9 | 6 | Associate degree | |
| | | 11.8 | 12 | Graduate and post graduate | |
| 0.71 | 0.57 | 53.46 | 54 | Yes | History of hospitalization |
| | | 46.54 | 47 | No | |
| *0.02 | 0.22 | 39.6 | 40 | Yes | History of surgery |
| | | 60.4 | 61 | No | |
| 0.41 | 0.05 | 29.7 | 30 | A+ | Blood type |
| | | 0.99 | 1 | A- | |
| | | 26.74 | 27 | B+ | |
| | | 0.99 | 1 | B- | |
| | | 13.86 | 14 | AB+ | |
| | | 0 | 0 | AB- | |
| | | 27.72 | 28 | O+ | |
| | | 0 | 0 | O- | |

*Significance level below 0.05 is considered.

**Table 1. Demographic indicators of patients with Beta-thalassemia and its relationship with quality of life and family cohesion using independent t-test and ANOVA.**

| r | P value* | Mean and SD | Dimensions of health |
|---|---|---|---|
| 0.004 | 0.97 | 83.16±17.89 | Physical function |
| 0.06 | 0.53 | 72.77±32.22 | Role disorder due to physical health |
| 0.06 | 0.49 | 7.27±34.93 | Role disorder due to emotional health |
| -0.03 | 0.72 | 66.68±23.26 | Energy/Fatigue |
| -0.02 | 0.82 | 71.06±20.92 | Emotional well-being |
| 0.03 | 0.75 | 72.62±23.08 | Social function |
| -0.04 | 0.66 | 83.09±20.22 | Pain |
| -0.09 | 0.32 | 63.93 ±20.50 | General Health |
| -0.08 | 0.93 | 75.71±16.20 | Physical Health |
| 0.02 | 0.82 | 70.20±20.73 | Mental Health |
| 0.02 | 0.79 | 72.28±17.25 | Total quality of life score |

* Significance level below 0.05 is considered.

**Table 2. Mean scores and standard deviation of the eight dimensions of quality of life related to health, physical health, mental health and the total score of quality of life and spiritual health and their correlation with each other.**

There was no statistically significant correlation between quality of life and its dimensions and total family cohesion score (P >0.05) (**Table 2**).

## Discussion and Conclusion

Thalassemia is the most common chronic inherited disease that occurs in almost all population races.[14] Expensive lifelong treatment combined with poor quality of life due to this disease has an adverse effect on families.[32] The total score of life quality for patients with beta-thalassemia major in the present study, which was assessed by SF-36 questionnaire, was 28.72 ± 25.17. In the study of TORT et al., The mean total score of quality of life of patients with the beta-thalassemia major from Turkey was 2.59±4.12.[33] In the study of Bazi et al., The total quality of life score of patients with thalassemia major was 4.51± 3.13.[34] Other studies also expressed the lower quality of life in patients with thalassemia major compared to healthy individuals.[35,36] High quality of life in patients of our study compared to Previous studies may indicate more attention to thalassemia major patients by health centers and their surroundings at this time. However, geographical and cultural differences may also affect the quality of life of thalassemia patients worldwide.

In this study, the mean total score of family cohesion was 63.4± 81.1, which indicates the average level of family cohesion and cohesion in these patients. Kaheni's study found that lower quality of life in children with thalassemia affects family cohesion.[37] Effective problem management largely depends on how the family's function.[38] The role of the family as the most protective institution against the challenges of life is undeniable. Therefore, with

appropriate interventions, steps can be taken to improve the cohesion of patients' families in order to reduce the mental and physical problems of patients with thalassemia major and lead to improving the level of their activities. In this study, no statistically significant correlation was observed between the quality of life and its dimensions and total family cohesion score.

In a national study et al, A direct relationship was reported between family functioning and emotional well-being of children with thalassemia major.[39] In another study, a significant relationship was observed between the quality of life and family financial support in patients with beta-thalassemia major.[40] Family performance is a factor influencing the mental status of these patients.[41] Patients, their families, and the multidisciplinary team should work together to optimize self-care and improve quality of life. Based on the analysis, a statistically significant relationship was found between marriage and quality of life. HaghPanah's study showed that marital status did not have a significant effect on patients' SF-36 scores.[15] In the study of TORT et al, there was no statistically significant difference between SF-36 scores of married and single patients.[33] It can be explained by demographic differences that by studying a higher statistical sample size, it is possible to determine the result with higher confidence.

Family functioning is widely accepted as an important concept that is believed to play a vital role in the care of patients with chronic diseases including thalassemia. The family is a powerful natural support system for patients with thalassemia and other family members. Thus, these understanding guides health care providers to integrate these factors to develop an effective intervention to strengthen family functioning in families living with children with thalassemia.

The final result of the present study showed that there is no statistically significant correlation between the quality of life and its dimensions and the total score of family cohesion in patients with thalassemia major in Behbahan. Evaluation of indicators and factors related to the quality of life in patients with thalassemia major is an essential first step in optimizing clinical and psychological support. As limitations of the present study, we can mention the collection of data over a period of time and the limited number of participants in the study, and non-random sampling. Finally, it is suggested that studies be conducted to investigate the effect of interventions that improve the quality of life and family cohesion in patients with thalassemia major. Considering other patient groups will also help in more accurate planning.

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