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# Quality of life among patients with beta-thalassemia major in Shahrekord city, Iran

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## ABSTRACT

**Background and aims:** Nowadays introduction of regular blood transfusion therapy has obviously improved the life expectancy of patients with thalassemia. However, these patients face with newer challenges which influence their quality of life (QoL). In this study, the aim of this study was to measure QoL among patients with β-thalassemia major (β-TM).
**Methods:** A cross-sectional study was done at the thalassemia centre of Shahrekord University of Medical Sciences. All the forty patients with β-thalassemia which were more than 12 years old referred to blood transfusion and participated in this study. Then, they were asked to fill out the Short Form Health Status Survey (SF-36) questionnaire. The questionnaire evaluates 8 health areas including physical functioning (PF), role-physical (RP), bodily pain (BP), general health (GH), vitality (VT), social functioning (SF), role-emotional (RE) and mental health (MH). The scores of each participant were calculated and data were analyzed using SPSS.
**Results:** There were 18 men and 22 women, and the mean age was 21.69±5.74 years (range 12-38). No significant difference was seen in QoL between men and women (68.72±19.79 versus 67.47±18.80, P=0.84). The mean±SD score of PF, RP, BP, GH, VT, SF, MH was 80.5±16, 83.75±29.17, 71.94±24.22, 57.48±23.93, 54.36±22.51, 68.94±23.37, 66.33±36.04 and 58.51±23.68, respectivly. No significant differences were detected in all mentioned scores between men and women (P>0.05).
**Conclusion:** Although most of the participants had suitable physical functioning, thalassemia had a negative effect on emotional role, social functioning and mental health of patients. It shows the importance of psychosocial supports for these patients.

**Keywords:** Beta-thalassemi, Quality of life,SF-36 questionnaire.

Original article

## INTRODUCTION

Thalassemia is the most common genetic disorder worldwide and is regarded as an important problem in public health issues in the Mediterranean region There are over 20,000 people of different ages with thalassemia major in Iran with a prevalence of one to ten percent in different parts of Iran Nowadays, with improvements in the therapeutic strategies of patients with beta-thalassemia, these patients have a longer life expectancies and the prolonged survival of these patients makes their quality of life (QoL)

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as an important issue.[1-4] There are many reasons such as chronicity of the disease, treatment costs, absence of sexual development, infertility, inability to raise their own family and expected early death that cause psychosocial problems in patients with thalassemia.[3,5] In order to improve QoL of these patients, programs was aimed to provide psychological supports which are needed.[2,6] The QoL should be considered as an important index of effective treatment. The evaluation of QoL differs from other forms of medical evaluations in that it focuses on the individuals' own views of their well-being. Therefore, determining QoL of these patients leads to better understanding of their specific needs and using more effective care.[2,7]

As Iran has a high prevalence of thalassemic patients, efforts for improving their status especially in psychosocial area with effective interventions are needed. In this way evaluation of the QoL is the first step in this regard. The better we know about their QoL, the easier we can make program for sufficient interventions for improving these patients' status.

In this study we want to evaluate the quality of life among patients with beta- thalassemia major in Shahrekord city, Iran.

## METHODS

In this cross-sectional study, all the 40 patients with β-TM who were being transfused at the thalassemia ward of Hajar Hospital of Shahrekord University of Medical Sciences were selected during 2013. All the patients were more than 12 years old and had been transfusion-dependent. The diagnosis had been made according to their hemoglobin electrophoresis results. The study protocol was approved by the Ethics Committee of Shahrekord University of Medical Science. The aim of the study was explained for all the patients and verbal consents were obtained.

The patients' demographics information, including age, sex and marital status were recorded.

The Persian version of the SF-36 questionnaire which was already translated and validated by Jafari et al with a Cronbach's alpha coefficient (a=0.93) was used in this study. The SF-36 is a self-administered QoL scoring system which consists of eight independent scales and two major dimensions. The eight multi-item scales include physical functioning (PF), role-physical (RP), bodily pain (BP), general health (GH), vitality (VT), social functioning (SF), role-emotional (RE) and mental health (MH).[8] The first five scales are summarized into the physical health dimension and the last three scales into the mental health dimension.[9] The score given to QoL in each domain varies between zero to 100; a score close to zero shows a worse QoL and the one close to 100 shows a better QoL. All patients were asked to fill out the questionnaire. Data were analyzed using descriptive statistics (frequency, mean, and standard deviation) with SPSS software.

## RESULTS

A total of 40 patients were collected and participated in this study. All of participants filled out the questionnaire. From these, 18(40%) were males, and 22(60%) were females. The mean age of the subjects was 21.69±5.74 years (ranging from 12-38 years). Two (5%) were married and 38 (95%) were single.

Total QoL of the participants was not high (68.06±18.96) and it was not significantly different between male and female participants (68.72±19.79 vs 67.47±18.80, P=0.84).

The mean GH score was 57.48±23.93. Regarding general health, the patients asked about their overall general health. Three (7.5%) patients said that their GH was excellent, 13(32.5%) felt very good, 12(30%)

felt good, 9(22.5%) felt fair and 3(7.5%) felt bad.

The mean PF score was 80.5±16. Regarding PF, patients were asked about the activities such as walking, bathing, dressing and climbing stairs. All of participants said that there were no limitations for them for bathing or dressing, but 9(22.5%) had limitations for walking only one block and 23(57.5%) subjects had limitations for climbing several stairs.

The mean RP score was 83.75±29.17. Regarding to this territory, 27(67.5%) subjects received 100 scores and only 3(7.5%) got zero score.

The mean BP score was 71.94±24.22. Nine(22.5%) patients felt no pain and 2(5%) said that pain had adversely interfered with their normal work during the past 4 weeks.

The mean SF score was 68.94±23.37. About the question 'Do emotional problems interfere with your normal social activities with family, friends, neighbors or groups?' 14(35%) chose the answer "not at al," 10(25%) chose "slightly," 8(20%) chose "moderately", 7(17.5%) answered "sever" and 1(2.5%) answered "very sever."

The mean VT score was 54.36±22.51. Fifteen (37.5%) subjects received scores below 50 in this territory. About the question 'Did you have a lot of energy?', a quarter (10 subjects) chose the answer "all of the time" or "most of the time" and 5 subjects chose "none of the time."

The mean RE score was 66.33±36.04. Fifteen (37.5%) participants said that they worked less carefully than usual.

Regarding to MH, the mean score of this item was 58.51±23.68.The participants were asked to answer if they had been a happy person. Thirteen (32.5%) subjects responded that they had been happy all of the time or most of the time and eight (20%) felt happy 'a good bit of time'. Two (5%) said that they had never been happy and eight (20%) felt happy a little of the time. The others responded "some of the time."

No significant differences were found between male and female participants in all the mentioned items (P<0.05) (Table-1).

**Table 1:** Health-related quality of life of the patients with beta-thalassemia major in Shahrekord City, Iran

| Variable | Total | Men | Women | P |
|---|---|---|---|---|
| Physical functioning | 80.50±16 | 79.17±16.89 | 81.59±15.99 | 0.646 |
| Role-physical | 83.75±29.17 | 87.50±27.45 | 80.68±30.79 | 0.464 |
| Bodily pain | 71.94±24.22 | 75.15±20.73 | 69.45±26.81 | 0.459 |
| General health | 57.48±23.93 | 57.37±20.10 | 57.57±27.14 | 0.979 |
| Vitality | 54.36±22.51 | 52.06±23.05 | 56.14±22.46 | 0.583 |
| Social functioning | 68.94±23.37 | 75.34±21.00 | 61.11±24.21 | 0.058 |
| Mental health | 58.51±23.68 | 58.65±24.04 | 58.41±23.96 | 0.976 |
| Role emotional | 66.33±36.04 | 62.96±35.94 | 63.63±36.96 | 0.954 |
| Total SF-36 | 68.06±18.96 | 68.72±19.79 | 67.47±18.80 | 0.844 |

# DISCUSSION

Beta-thalassemia is a genetically inherited disorder characterized by reduced synthesis of the beta-hemoglobin chain which results in reduced synthesis of hemoglobin A.[10] It can be a potentially life-threatening disease, but advances in treatment have increased life expectancy. However, the need for chronic blood transfusions and chelation therapy remains a burden for these patients.[11] Despite advancements in care, transfusion-dependent patients still present complications and often suffer from psychological problems. It shows

the importance of developing QoL of these patients in addition to life support strategies.[10]

Fourty patients with beta-thalassemia who all were transfusion-dependent, took part in this study. Most of them were single in agreement with other studies.[10,12] cardiological disorders, diabetes mellitus, hepatitis, dependency on periodic blood transfusion and infertility are the common causes.[5]

The current study shows intermediate mean QoL in patients with major thalassemia. This finding is similar to the results of some studies conducted in Iran, but another study conducted by Haghpanah et al shows low mean QoL in these patients.[2,5] Such inequalities are because of differences of the physical conditions among thalassemic patients.

Most of the participants showed to have higher scores in items evaluating physical health than mental health. It can be due to regular blood transfusion and using deferoxamine which can improve the physical health status, but developing mental health is depending on social supports.[5,15] The results of this study found that many of the patients with thalassemia major suffered from loss of energy, anger and sadness. This might be due to the chronicity of the disease, unemployement, infertility and many other factors that can influence mental health. It is consistent with the findings of other studies.[13,14] These patients had low or intermediate mean scores in all scales except in PF and RP. Similar to our study, Haghpanah et al reported low mean scores in other scales except PF in patients with thalassemia major.[5]

Differing from our results, Sobota et al found worse QoL and lower scores in women.[11] In the study conducted by Haghpanah et al women had lower scores on BP and RE.[5] However, Hadi et al reported better scores in women.[16] Problems resulting from thalassemia and its treatment are not different between men and women. Equality in treatment especially iron chelating can be the reason of same scores in men and women in this study.

One limitation of this study was the lack of control group for comparing QoL of thalassemic patients and normal population. In addition, because of unequal culture, these findings are not representative of all thalassemic patients in Iran. This shows that different interventions are needed for improving quality of life among these patients in different areas and cities and the first step for programming these interventions is evaluating the quality of life among patients with thalassemia.

## CONCLUSION

B-thalassemia major widely influences on Qol of patients. So, health promotion supports especially in psychosocial area is needed for these patients and focusing on blood transfusion or iron chelating agents is not sufficient.

## CONFLICT OF INTEREST

The authors declare no conflict of interest.

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