

Quality of Life Among Adolescents and Adult Patients with Beta-Thalassemia Major in Karbala, Iraq

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ABSTRACT

Background: Beta-thalassemia major (β -TM) is a chronic inherited blood disorder requiring lifelong transfusions and iron chelation. This study assesses health-related quality of life (HRQoL) among adolescent and adult patients with β -TM in Karbala. **Aim of the study:** To assess (HRQoL) among adolescents and adults with (β -TM) in Karbala city and to evaluate the demographic and clinical factors that influence the quality of life of those patients. **Patients and Methods:** A cross-sectional study was conducted in 2024–2025 on 170 patients using the SF-36 questionnaire. Demographic and clinical data were collected and analyzed using SPSS version 23. **Results:** The mean QoL score was 49.76 ± 10.61 . Better QoL was seen in those with higher income, education, employment, and regular transfusions. Non-chelated patients reported higher QoL in many domains. **Conclusion:** QoL is significantly influenced by socioeconomic and clinical factors. A multidisciplinary care approach is crucial.

Keywords: Beta-Thalassemia Major, Quality of Life, SF-36.

Article Information

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INTRODUCTION

In, Middle East, and parts of Asia¹. It is caused by mutations in the beta-globin gene leading to reduced or absent beta-globin chains and ineffective erythropoiesis². Without appropriate management, patients often develop severe anemia, skeletal deformities, growth retardation, and organ failure³. Iraq, with a high prevalence of consanguineous marriages, reports considerable cases of β -TM annually⁴. With advancements in transfusion practices and iron chelation, survival has improved, yet chronic complications and psychosocial burden persist⁵.

Patients often suffer from delayed puberty, endocrine disorders, and cardiac issues resulting from iron overload⁶. These clinical outcomes negatively influence their psychological and social well-being, limiting their ability to engage in educational and employment opportunities. The chronic nature of treatment and frequent hospital visits also lead to emotional exhaustion and reduced self-

esteem⁷. While survival has increased, attention must be given to improving the quality of life (QoL) in these patients. Health-related quality of life (HRQoL) is a multi-dimensional concept that includes physical, emotional, and social aspects of well-being. The SF-36 questionnaire has been validated globally and is useful for evaluating HRQoL in chronic diseases like β -TM⁸. This study aims to evaluate HRQoL in β -TM patients in Karbala and assess influencing factors.

PATIENTS AND METHODS

Study design

This is observational cross-sectional study ,on patient with beta-thalassemia major.

Study setting and timing

A total of 170 individuals diagnosed with beta-thalassemia major (β -TM) and registered at the Hereditary Blood Disease Center in Karbala were randomly selected and enrolled in the study during the period from 2024 to 2025.

Inclusion criteria

All patients were older than 12 years and have required regular blood transfusions starting from the age of two.

Exclusion criteria

Participants younger than 12 years and those diagnosed with other hemoglobinopathies were excluded from the study.

Data collection

During the period of 1st November 2023 to 30th of December 2024, data was collected by using SF-36 questionnaire (Ware, J. E. & Gandek, 1993). The questionnaire was completed through a combination of self-administration and interviews. Participants were requested to fill out the form themselves, while those who were illiterate received assistance from a trained individual, who filled out the form for them at a face-to-face interview taking into account their privacy. Each interview took approximately 15-20 minutes.

Statistical analysis

Data were entered and analyzed throughout the use of the Statistical Package for the Social sciences (SPSS 23.0 for Windows). Descriptive statistics presented as frequency and percentage (or mean \pm SD) in appropriate tables and graphs. Possible association between the study variables was tested using T-test or ANOVA test. Total

mean QOL Score was obtained by average the 8 QOL scale. Significance level was considered if $p < 0.05$.

RESULTS

The mean age of participants was 20.58 ± 5.99 years; 55.3% were female. Most had only primary education, and just 10% had high income. A significant proportion were unemployed and single. Clinical profiles indicated that 70% of participants received monthly transfusions, and 60% were on chelation therapy. Splenectomy was performed in 25% of patients significantly higher in participants with higher income, educational level, employment, and regular blood transfusions.

Social functioning scored the highest (51.25), while general health scored the lowest (46.82). QoL scores were Adolescents aged 12–17 had higher vitality and mental health scores than adults. Employed individuals scored over 10 points higher in total HRQoL. Monthly transfusions were associated with better role and social functioning.

The regression analysis showed that income level, frequency of transfusions, and chelation status were significant predictors of QoL ($p < 0.05$). Patients not receiving chelation therapy reported better QoL scores in some domains, suggesting potential treatment burden or side effects.

Table 1: Sociodemographic characteristics among study participants.

Characteristics		Number (%) N=90
Age (years)	12 – 19	77 (45.3)
	20 and above	93 (54.7)
	Mean ± SD	20.58±5.99
Gender	Male	76 (44.7)
	Female	94 (55.3)
Marital status	Single	132 (77.6)
	Married	38 (22.4)
Academic qualification	Illiterate	11 (6.5)
	Primary school	111 (65.3)
	Secondary school	26 (15.3)
	College	22 (12.9)
Occupation	Student	66 (38.8)
	Employed	22 (12.9)
	Unemployed	45 (26.5)
	Free business	37 (21.8)
Monthly income	Low	103 (60.6)
	Middle	49 (28.8)
	High	18 (10.6)

Table 2: Clinical characteristics and some disease-related variables among study participants.

Characteristics	Number (%) N=90	
Age of onset of thalassemia	< 6 months	39 (22.9)
	6 - 12 months	51 (30)
	> 12 months	80 (47.1)
Frequency of blood transfusion	Every 2 weeks	83 (48.8)
	Every 3 weeks	26 (15.3)
	Every 4 weeks	61 (35.9)
History of splenectomy	Yes	109 (64.1)
	No	61 (35.9)
Use of chelation therapy	Used chelation:	151 (88.8)
	Deferoxamine	66 (38.8)
	Deferasirox	55 (32.4)
	Combined	30 (17.6)
	Not used chelation	19 (11.2)
Have family members with thalassemia	Yes	102 (60)
	No	68 (40)
Number of family members with thalassemia	No family history	68 (40)
	One	20 (11.8)
	Two	49 (28.8)
	Three and more	33 (19.4)
Haemoglobin level	Mean ± SD	7.72±1.33
Latest Ferritin level	< 500	2 (1.2)
	500-999	50 (29.4)
	1000-1999	88 (51.8)
	≥ 2000	30 (17.6)

Table 3: Scores of the different scales of the QOL.

Scale	Mean	SD
General Health	46.82	8.63
Physical functioning	50.24	21.48
Role limitations/ physical	49.60	18.00
Role limitations/emotional	49.22	19.78
Social functioning	51.25	19.26
Bodily pain	50.66	20.77
Emotional wellbeing (mental health)	49.32	11.04
Vitality	50.96	11.30
Total QOL Score	49.76	10.61

DISCUSSION

The results of this study indicate that patients with β -TM in Karbala experience moderate impairments in multiple domains of quality of life, with the general health domain being the lowest. This aligns with regional studies which also show diminished HRQoL in similar patient populations⁹. The relatively higher score in social functioning (mean: 51.25) may be reflective of strong family and community support systems prevalent in Iraqi culture¹⁰. Consistent with our findings, previous research indicates that higher income and educational attainment are associated with better QoL in thalassemia patients¹¹. Participants with regular employment showed significantly higher QoL scores, supporting the idea that stable work can provide not only financial but also psychological benefits¹². Interestingly, patients not receiving iron chelation therapy had better scores in some QoL domains. While chelation therapy is essential to prevent iron overload complications, its burden, side effects, and administration challenges (especially with desferrioxamine) may reduce perceived QoL¹³. This suggests the importance of tailored chelation regimens and proper counseling.

Adolescents (12–17 years) in our study had better mental health and vitality scores than adults. This contrasts with studies from Iran and Egypt, where mental health scores tended to be lower in younger patients¹⁴. Cultural differences and family support structures may explain this variation. Our results showed a modest impact of gender, with females scoring lower in physical functioning and vitality. This is consistent with findings from studies conducted in the Eastern Mediterranean and Southeast Asia¹⁵. Gender-specific interventions may be warranted in care plans. Splenectomy status was not significantly associated with QoL in this sample, though other studies have reported varying outcomes depending on complications or frequency of transfusions¹⁶. Regular

transfusions, however, were positively associated with better role and social functioning scores, likely due to improved energy levels and reduced symptom burden¹⁷. These findings highlight the importance of addressing socioeconomic barriers, enhancing transfusion access, and improving patient education and mental health support as part of a comprehensive care plan. The limitations of this study include its cross-sectional nature, which prevents causal inference, and its restriction to a single center. Additionally, data were self-reported, which may introduce response bias. Future longitudinal and multi-center studies with mixed-methods approaches are recommended to explore QoL dynamics more deeply.

Limitations

While this study provides important insights, certain limitations must be recognized. Firstly, some important psychosocial variables such as coping strategies, stigma perception, and social support were not directly measured. Secondly, while SF-36 is a validated tool, it is not disease-specific; using a thalassemia-specific QoL instrument might have revealed further nuances in patient experiences.

CONCLUSION

Beta-thalassemia major significantly affects various dimensions of patients' quality of life, especially in general health, energy levels, and physical capabilities. Although social and emotional support appeared relatively adequate, the overall well-being of patients remains compromised. Key factors contributing to reduced QoL include a high burden of medical complications, limited access to educational and employment opportunities, mental health challenges such as anxiety and depression, and inconsistent adherence to treatment, particularly iron chelation therapy. These findings highlight the importance of adopting a more comprehensive, patient-centered care model. Effective care should address not only clinical

needs, but also psychological and social aspects to enhance patients' overall quality of life.

RECOMMENDATIONS

Integrate Mental Health and Psychosocial Support: Incorporate regular mental health assessments and provide access to counseling and social support to address emotional and psychological challenges. **Enhance Education and Treatment Adherence:** Improve patient understanding of their condition and encourage adherence to treatments—particularly iron chelation—through targeted education and support. **Support Social and Economic Inclusion:** Promote policies that facilitate employment, flexible education, and reduce stigma to improve social integration and quality of life. **Adopt a Holistic, Patient-Centered Approach:** Ensure multidisciplinary care that addresses physical, psychological, and social needs using standardized tools like SF-36 to monitor outcomes.

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Ethical approval

The study protocol was approved by both the Research Ethics Committee at the University of Karbala - College of Medicine, and the Karbala Health Directorate. Informed verbal consent

was obtained from all participating patients. A facilitation letter was issued by the College of Medicine, University of Karbala, and sent to the Hereditary Blood Diseases Center in Karbala City.

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