Ministry of Higher Education &
Scintific Research
University of Kerbala
College of Medicine
Department of Family & Community Medicine

Quality of Life of Adolescent and Adult Patients with Beta-Thalassemia major at the Hereditary Blood Center in Kerbala City, 2024

A Thesis

Submitted to the Council of College of Medicine – University of Kerbala in partial fulfilment of the Requirements for the higher diploma (two calendar years) in family medicine

By

RUSUL AMER HAMMOODI

M.B.Ch.B.

Supervised by

Assistant Professor
Dr. Shahrazad S. AL Jobori
M.B.Ch.B, F.I.B.M.S. (CM)

Assistant Professor
Inas Muayad Mohammed Ali
M.B.Ch.B C.A.B.P

1447 H.D

2025 A.D

بسم الله الرحمن الرحيم

"يَرْفَعِ اللَّهُ الَّذِينَ آمَنُوا مِنكُمْ وَالَّذِينَ أُوتُوا الْعِلْمَ دَرَجَاتٍ وَاللَّهُ بِمَا تَعْمَلُونَ خَبِيرٌ"

صدق الله العلي العظيم

«سورة المجادلة: الآيات 11»

Certification of Supervisor

We certify that this thesis which was prepared by **RUSUL AMER HAMMOODI** at the Department of Family and Community Medicine, College of Medicine, University of Kerbala, as partial fulfilment of the requirement for the degree of Higher Diploma (two calendar years) in Family Medicine.

Signature

Assistant Professor

Dr. Shahrazad S. AL Jobori

M.B.Ch.B, F.I.B.M.S. (CM)

Signature

Assistant Professor

Dr. Inas Muayad Mohammed Ali

M.B.Ch.B C.A.B.P

In the view of the available recommendation, I forward this thesis for debate by the examining committee.

Signature

Dr. Shahrazad S. AL Jobori

Head of family and community medicine department

College of medicine -University of Kerbala

Certification of Committee

We the examining committee, certify that after reading this thesis and have examined the student **RUSUL AMER HAMMOODI** in this content, and that in our opinion it meets the standard and requirement of the thesis in the partial fulfillment for the degree for the Higher Diploma (2 calendar years) in family medicine.

Prof. Dr.
Qais Ismaeel Kadhem
College of Medicine
University of Babylon
(Member)

Asst. Prof. Dr.
Inas Muayad Mohammed Ali
College of Medicine
University of Kerbala
(Supervisor/Member)

Prof. Dr.
Ali Mousa Al Mousawi
College of Medicine
University of Kerbala
(Member)

Asst. Prof. Dr.
Shahrazad S. AL Jobori
College of Medicine
University of Kerbala
(Supervisor/Member)

Prof. Dr.
Usama Ahmed Hadi
College of Medicine
University of Kerbala
(Chairman)

Approved by
College of Medicine/ University of Kerbala
As a thesis for the degree of higher diploma in Family Medicine
Prof. Dr. Khalid Khalil Al-Araji
Dean of
College of Medicine/ University of Kerbala

Dedication

To my parents, whose unwavering support and values of hard work and perseverance instilled in me have been the foundation of my journey and my deepest gratitude.

To my beloved husband, whose patience, encouragement, and understanding during the course of this research meant the world to me, I am truly thankful.

Acknowledgments

I would like to express my sincere gratitude to all who contributed to the completion of this thesis. First and foremost, I extend my heartfelt thanks to my dedicated and knowledgeable supervisors, Dr. Shahrazad S. Al-Jobori, and Dr. Inas Muayad Mohammed Ali for their continuous guidance, support, and insightful feedback throughout the course of my research. Their encouragement and constructive critiques were instrumental in shaping this work. I am especially grateful to my husband, whose invaluable assistance in data collection made this study possible, and to my father, whose support in completing the necessary procedures was deeply appreciated. Without their help, this work would not have been accomplished

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Abbreviations	Meaning
β-TM	Beta-Thalassemia Major
BMT	Bone Marrow Transplantation
CI	Confidence Interval
GVHD	Graft-Versus-Host Disease
Hb	Haemoglobin
HbA	Adult Haemoglobin
HRQoL	Health-Related Quality of Life
IQR	Interquartile Range
p-value	Probability Value
QoL	Quality of Life
RBC	Red Blood Cell
SD	Standard Deviation
SF-36	Short Form-36 Health Survey
SPSS	Statistical Package for the Social Sciences
TIF	Thalassemia International Federation
WHO	World Health Organization
WHOQOL-BREF	World Health Organization Quality of Life Brief Version
β-TM	Beta-Thalassemia Major

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Abstract

Background: Beta-thalassemia major (β-TM) is a chronic hereditary blood disorder requiring lifelong blood transfusions and iron chelation therapy. It significantly affects the quality of life (QoL), especially in resource-limited settings.

Objective: This study aims to assess the health-related quality of life (HRQoL) among adolescent and adult patients with Beta-thalassemia major in Kerbala, Iraq, and to identify associated demographic and clinical determinants.

Methods: A cross-sectional study was conducted at the Hereditary Blood Diseases Center in Kerbala between 1st November 2023to 30th of December 2024.A total of 170 patients aged ≥12 years were enrolled in the study. Data were collected using the Arabic version of the Short Form-36 questionnaire, with additional World Health Organization Quality Of Life -BREF items. Statistical analysis was performed using SPSS version 23.

Results:

No significant differences in quality of life (QoL) were found concerning age or gender. Single, educated, employed participants and those with higher income showed better QoL scores. Patients with later disease onset and those receiving more frequent blood transfusions had improved QoL, while unexpectedly, individuals not on chelation therapy reported higher scores in several domains.

Conclusion: Quality of Life in β-TM patients are significantly influenced by socioeconomic and clinical factors. Comprehensive, multidisciplinary care—especially addressing mental health and social integration—is essential to improve overall well-being.

CHAPTER ONE

INTRODUCTION

1.1 Introduction:

Thalassemia is a heterogeneous group of inherited hemoglobinopathies caused by mutations or deletions in the α- or β-globin genes, leading to insufficient or defective synthesis of globin chains and resulting in ineffective erythropoiesis, chronic hemolysis, and varying clinical severity **(Babangida et al. 2024**). The disease is inherited in an autosomal recessive manner in most clinically significant cases, meaning that an individual must inherit pathogenic alleles from both parents to manifest the phenotype **(TIF guidelines 2021).**

Among the thalassemia types, beta-thalassemia is particularly prevalent in the Mediterranean basin, the Middle East, South Asia, and parts of Africa. Beta-thalassemia major (β-TM), also known as Cooley's anemia, represents the most severe clinical phenotype, typically presenting in early childhood with profound anemia requiring regular blood transfusions to sustain life **(Cappellini et al, 2020).** Beta-thalassemia minor, or the carrier state, is usually asymptomatic but plays a crucial role in disease transmission through population genetics.

Globally, estimates suggest that approximately 1.5% of the world's population are carriers of thalassemia-gene mutations, placing the overall burden of hemoglobinopathies among the most common inherited disorders **(Babangida et al. 2024).** In Iraq, the estimated number of registered β-thalassemia major patients is about 15,000, with prevalence rates varying by region: in Erbil the rate rose from 30.8/100,000 in 2015 to 37.3/100,000 in 2020, while all hemoglobin disorders in that region increased from 31.9/100,000 to 42.7/100,000 in the same period **(Iraq Erbil Study, 2022)**. β-Thalassemia carrier rates in Baghdad have been documented at approximately 3.5% through premarital screening programs, and in the Kurdish regions between 3.7–6.9%, depending on governorate **(Baghdad Premarital Screening, 2024; Kurdish Genetic Epidemiology, 2021).**

Clinically, β-thalassemia major usually presents in infancy or early childhood with severe anemia, failure to thrive, jaundice, pallor, and hepatosplenomegaly resulting from extramedullary hematopoiesis **(Thalassemia Pathophysiology Review, 2022).** Bone marrow expansion leads to skeletal deformities, especially in the skull and facial bones, producing characteristic facial changes such as frontal bossing, depressed nasal bridge, maxillary overgrowth, and classic "thalassemic facies" **(Amjad et al., 2024)**. In addition, patients are at risk of osteoporosis and vertebral compression fractures, contributing to chronic pain and reduced mobility, even in those receiving transfusion and chelation therapy **(Alpha- and Beta-thalassemia: Rapid Evidence Review, 2022).**

Several studies report that these deformities lead to social withdrawal, bullying, and decreased confidence, which may in turn exacerbate anxiety and depression **(Khoury et al., 2011; Zare et al., 2015).**

Regular blood transfusion therapy substantially improves survival and reduces complications arising from chronic anemia in β-thalassemia major; however, it inevitably results in progressive iron overload. Excess iron is deposited in vital organs—namely the heart, liver, and endocrine glands—leading to serious conditions such as cardiomyopathy, hepatic fibrosis, diabetes mellitus, and hypogonadism **(Coates et al. 2025; Thalassemia cardiomyopathy review 2024; Pinto et al. 2020).** Iron chelation therapy using agents such as deferoxamine, deferiprone, or deferasirox is essential to mitigate iron toxicity and improve long-term outcomes **(Taher et al, 2019).**

Recent advancements in iron chelation therapies have significantly improved the management of iron overload in transfusion-dependent hematologic disorders **(Premawardhena et al., 2024).** Novel therapeutic strategies, including combination therapies and improved oral formulations, have addressed the limitations of conventional treatments, resulting in better patient outcomes **(Shah et al., 2017)**. For example, triple therapy with deferoxamine, deferasirox, and deferiprone has been shown to be both effective and safe in controlling iron overload **(Premawardhena et al., 2024).** Moreover, the introduction of a film-coated deferasirox tablet has enhanced patient adherence by reducing gastrointestinal side effects and improving bioavailability compared to the dispersible formulation **(Chalmers et al., 2016).**

Despite these improvements, challenges such as high cost, limited accessibility, and long-term adherence remain significant obstacles, emphasizing the need for ongoing research and global health initiatives **(Saliba et al., 2015).** Recent studies have also highlighted the underestimated risk of iron overload in non-transfusion-dependent thalassemia (NTDT) patients, underscoring the importance of early intervention with novel therapies like luspatercept to optimize clinical outcomes and quality of life **(Musallam et al., 2025).**

Studies show that consistent chelation therapy is directly correlated with better physical functioning, fewer cardiac complications, and improved survival. Patients receiving proper care can live into their fifth or even sixth decade, but they continue to struggle with chronic fatigue, hormone deficiencies, and psychological stress**.**

Bone marrow transplantation (BMT) offers a potential cure but is limited by donor availability, high cost, and risk of graft-versus-host disease (GVHD). Gene therapy, still under development, may offer future hope, but for now, the standard of care relies on transfusions and chelation **(Cappellini et al, 2020).**

Psychosocial complications are prevalent among individuals with thalassemia major, arising from the chronic nature of the disease, frequent hospital visits, and visible physical changes **(Alzahrani et al., 2022).** These factors contribute to increased rates of depression, anxiety, and social isolation, which can adversely affect treatment adherence and overall quality of life **(Gharaibeh et al., 2019).** Advancements in treatment have extended life expectancy beyond 40 years for many patients; however, this increased lifespan introduces new challenges related to education, employment, marriage, and fertility that require holistic, patient-centered care **(Taher et al., 2018).**

Reproductive health concerns have become prominent, with many patients experiencing fertility issues due to iron-induced endocrine dysfunction. In women, ovarian reserve assessment is essential for guiding fertility and hormonal management strategies **(De Sanctis et al., 2017).** Similarly, men with thalassemia major often face reduced testosterone levels and azoospermia, necessitating early hormonal screening and potential hormone replacement therapy to support development and improve life quality **(De Sanctis et al., 2019).**

In Middle Eastern societies, where family expectations are deeply ingrained, reproductive challenges further complicate marital prospects **(Al-Akhras et al., 2021).** Cultural stigma surrounding genetic conditions may deter potential partners, and many patients report fears of being perceived as "unfit" for marriage **(Gharaibeh et al., 2019) .**Studies from Lebanon, Jordan, and Egypt confirm that thalassemia patients—especially women—experience social rejection and self-doubt related to marriage and fertility**(Ezz El-Din et al, 2021).**

Several studies conducted across the Arab world and nearby regions have highlighted the significant psychosocial burden associated with beta-thalassemia major. In Egypt, **Ezz El-Din et al. (2021)** reported that nearly two-thirds of adolescent patients experienced moderate to severe psychological distress, with only a minority receiving consistent psychological support. Similarly, in Saudi Arabia, **Al-Suliman et al. (2016)** emphasized that poor adherence to treatment was prevalent among rural patients, leading to endocrine complications and increased school dropout rates.

In Jordan**, Al-Akour et al. (2017)** found that 40% of patients refrained from participating in social activities due to shame related to physical appearance or treatment procedures. Meanwhile, in Algeria, **Benmiloud et al. (2020)** noted that despite accessible public healthcare, patients continued to suffer from social stigma, limited educational opportunities, and restricted access to employment.

A recent Iranian study by **Asadi-Pooya et al. (2022)** revealed that many adult thalassemia patients scored significantly lower than the general population in physical and mental health domains, highlighting persistent challenges in achieving optimal quality of life even with modern treatment.

In Iraq, studies on health-related quality of life (HRQoL) among β-TM patients have highlighted substantial impairments in physical, emotional, and social functioning. For instance, **Al-Mosawi et al. (2021)** used the SF-36 questionnaire to reveal deficits in physical and emotional well-being. Similarly, **Kareem and Jasim (2020)** identified psychological distress and social dysfunction in Baghdad's patient population. Collectively, these studies suggest that despite clinical improvements and broader access to treatment, beta-thalassemia patients continue to experience substantial psychosocial distress. Without comprehensive interventions addressing mental health, marriage counseling, educational integration, and social support systems, improvements in clinical care alone may not translate into better overall quality of life.

With advances in medical care, thalassemia has evolved from a fatal pediatric condition to a chronic disease marked by improved survival into adulthood, making the assessment of Health-Related Quality of life (HRQoL) increasingly vital. The HRQoL encompasses an individual's subjective evaluation of how their health condition and its treatment influence various aspects of daily life, including physical, psychological, and social well-being. This is particularly relevant in beta-thalassemia major (β-TM), where the burden of continuous medical management, side effects of therapy, and social restrictions create complex challenges for patients **(Basu et al, 2015).**

The Short Form-36 Health Survey (SF-36) is one of the most widely used tools for assessing health-related quality of life (HRQoL) in both general populations and individuals with chronic illnesses (Hassan et al., 2018). It consists of 36 items that evaluate eight health domains, grouped under two main dimensions: physical and mental health. Each domain is scored on a scale from 0 to 100, with higher scores indicating better perceived quality of life **(Hassan et al., 2018).**

In patients with β-TM, physical functioning is frequently compromised due to chronic anemia and persistent fatigue. Moreover, social functioning may be hindered by facial deformities, repeated medical visits, and stigma associated with the condition. Emotional domains such as vitality and mental health are also commonly affected, as patients cope with the psychological stress of lifelong treatment and illness burden **(Cappellini et al, 2012) (Basu et al, 2015).**

Comprehensive care for individuals with beta-thalassemia major extends beyond routine hematological management to include endocrine monitoring, cardiac evaluations, psychological counseling, nutritional support, reproductive health services, and social integration strategies **(Rund & Rachmilewitz, 2005).**This multidisciplinary approach is essential for empowering patients to live more autonomous and emotionally balanced lives, with better opportunities for education, employment, and relationships **(Eljedi et al., 2019).** Psychosocial support has been shown to play a pivotal role in improving mental health outcomes.

Adolescents and adults—particularly those dealing with visible deformities or fertility issues—often benefit significantly from structured psychological interventions. In Lebanon, psychosocial programs were associated with enhanced coping mechanisms and improved adherence to treatment, especially among female patients**.** Similarly, in Egypt, the implementation of school reintegration plans and peer support initiatives contributed to reduced dropout rates and improved social functioning **(Ezz El-Din et al., 2021).**

The Thalassemia International Federation (TIF) emphasizes a patient-centered care model with regular HRQoL assessments using tools like SF-36 **(Thalassemia International Federation, 2021).** They advocate for national registries, early diagnosis programs, psychosocial support, and coordinated care across specialties. The World Health Organization (WHO) similarly highlights the role of interdisciplinary teams in chronic disease management, especially in developing countries **(World Health Organization, 2020).**

Despite these efforts, most developing countries, including Iraq, still lack structured comprehensive care programs **(Lafta & Mohammed, 2023).** Care remains fragmented, with little coordination between hematology, psychiatry, endocrinology, and social services. Patients often face logistical, financial, and cultural barriers that hinder access to supportive care**.** Understanding the demographic and clinical determinants of QoL in local populations is critical to guiding future interventions.

Age, gender, education, income, parental consanguinity, and compliance with chelation therapy all appear to influence SF-36 outcomes **(Lafta & Mohammed, 2023).** By identifying the most vulnerable patient groups and domains most affected, health authorities can allocate resources more effectively and develop national action plans.

1.2 Study objectives:

- To assess the health-related quality of life (HRQoL) among adolescents (aged 12–19 years) and adults diagnosed with beta-thalassemia major in Kerbala City.
- To identify and evaluate the demographic and clinical factors that influence the quality of life in this patient population

CHAPTER TWO

PATIENTS AND METHODS

2.1 Study Design:

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

2.2 Study Setting and Timing:

Patients diagnosed with beta-thalassemia major (β-TM) and registered at the Hereditary Blood Disease Center in Karbala were contently selected and enrolled in the study during the period from 1st November 2023 to 30th of December 2024.

2.3 Sample Size:

The required sample size for this study was calculated using a standard statistical formula:

$$n = \frac{Z^2 \cdot p \cdot (1-p)}{E^2}$$

Where:

- n = required sample size
- Z = Z-score corresponding to the desired confidence level (typically 1.96 for 95%)
- p = estimated proportion (0.5 used when prevalence is unknown)
- E = margin of error (commonly 0.05)

Using Z = 1.96, p = 0.5, and E = 0.05, the minimum required sample size was calculated to be approximately 384. However, due to limited accessibility and feasibility, a total of 170 patients were randomly selected from the Hereditary Blood Diseases Center in Kerbala.

2.4 Inclusion Criteria:

All patients aged 12 years and above, who had been receiving regular blood transfusions since the age of two, were included in the study.

2.5 Exclusion Criteria:

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

2.6 Pilot Study:

A pilot project involving 10 participants was conducted in March 2024 to assess the validity of the questions and to determine the time needed for participants to complete answering the questionnaire. This pre-test aimed to identify and resolve any issues that might arise during data collection. Based on the pilot, some modifications were made to the questionnaire, including clarifications of certain terms. On average, participants took approximately 20 minutes to complete the questionnaire. Responses collected during the pilot study were excluded from the final analysis.

2.7 Data Collection:

During the period of 1st November 2023 to 30th of December 2024, data was collected by using SF-36 questionnaire. 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 20 mints.

2.8 Questionnaire Form:

- Demographic information was collected from the patients, including age, gender, marital status, educational level, and economic status. Clinical data comprised the use of iron-chelating therapy, history of splenectomy, and any coexisting chronic conditions.
- The study employed the Arabic version of the SF-36 Health Survey, which has been culturally adapted and validated in Iraq **(Alkhathlan A, et al 2024**). A recent study conducted in Basra assessed health-related quality of life among adolescents with non-transfusion-dependent thalassemia using this version, demonstrating high reliability and validity (Hamed et al., 2024).
- The SF-36 questionnaire comprises 36 items evaluating eight health domains grouped into two main dimensions:
    - Physical health: Physical Functioning (PF), Role Limitations due to Physical Health (RP), Bodily Pain (BP), General Health Perceptions (GH), and Vitality (VT).
    - Mental health: Social Functioning (SF), Role Limitations due to Emotional Problems (RE), and Mental Health (MH).
- Scoring: Each domain is scored quantitatively on a 0–100 scale, with higher scores indicating better perceived quality of life. For classification purposes, scores were interpreted as follows:
    - 0–33 = Low QoL
    - 34–66 = Moderate QoL
    - 67–100 = High QoL
- Additionally, two supplementary questions from the WHOQOL-BREF were included to provide a more comprehensive assessment of overall quality of life (Hamed et al., 2024).

2.9 Patients Consent and Ethical Approval:

The study protocol was approved by both research ethical committee at University of Kerbala - College of medicine and Kerbala health directorate. Informed verbal consent was obtained from all patients. A facilitation letter was sent from Kerbala University/College of medicine to hereditary blood diseases center in Kerbala city.

2.10 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 ± 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 eight QOL scale as significance level of $p < 0.05$.

CHAPTER THREE

RESULTS

This study involved 170 beta-thalassemia major patients from the Hereditary Blood Diseases Center in Kerbala pediatric hospital. The average age was 20.58±5.99 years. More than one half were female, and fewer than 25% were married. Around two-thirds had primary education or less, and only 10% reported high income. About 47% were diagnosed after 12 months of age. Nearly half received blood transfusions biweekly. Splenectomy was reported in two-thirds of cases, and most (88.8%) used chelation therapy. Additionally, 60% had a family history of thalassemia (table 3.1 and 3.2 below).

Table-3.1: The Sociodemographic Characteristics Among Thalassemia Patients in Kerbala (n=170)

Variables	**Groups**	**Frequency (%) n=170**
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-3.2: The Clinical Characteristics and Some Disease-Related Variables Among Thalassemia Patients in Kerbala (n=170)

Variables	**Groups**	**Frequency (%) n=170**
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)

The most common complication was Hepatitis C infection (22.35%), followed by hypogonadism (21.76 %), diabetes mellitus (20.59%), and psychiatric disorders (18.82%). Osteoporosis and hypothyroidism were also prevalent, reported in 17.06% and 15.88% respectively. Hepatitis B infection (10%) and cardiac disease (8.24%) were the least common. These findings suggest that viral infections and endocrine disorders were more frequent than cardiac complications in this patient group.

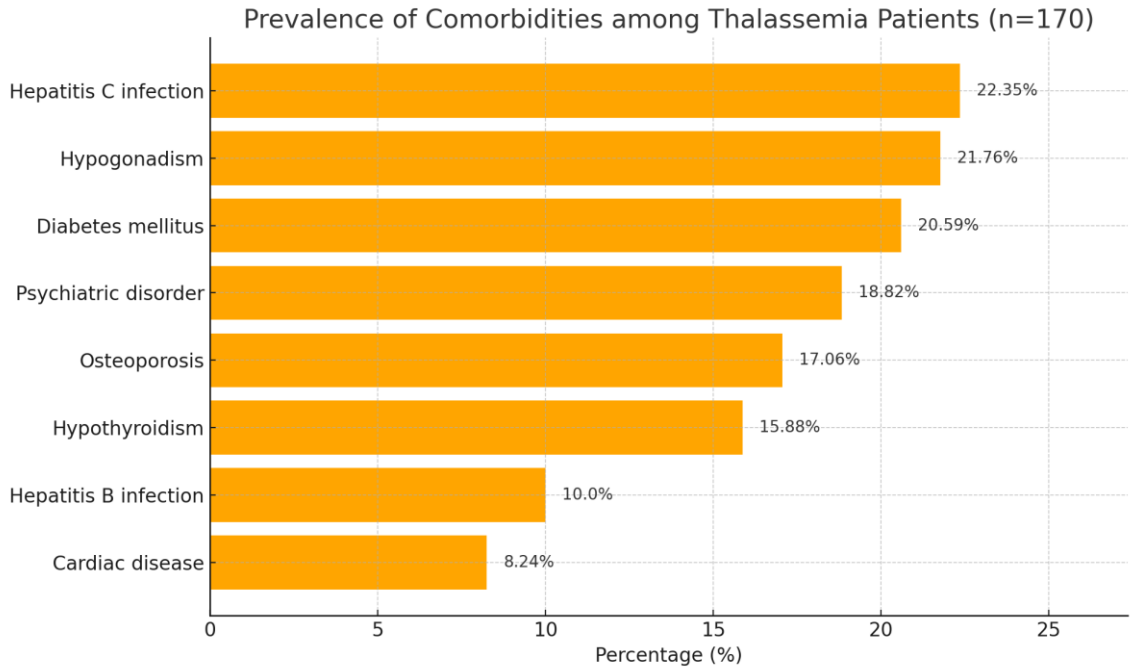

Figure 3.1: The Percentage of comorbidities among thalassemia patients in Kerbala (n=170).

3.3 Participants' Self-Rated General Health: Responses to the First Two SF-36 Questions

Regarding self-rated general health, more than half of the participants (53%) reported their health as fair or poor. Furthermore, the majority of participants (70%) stated that their health remained about the same compared to one year ago (table 3.3).

Table-3.3: The Answers to the First Two Questions of the 36-Item Health Survey Questionnaire Among Thalassemia Patient in Kerbala(n=170)

Items in the questionnaire	**Choices (Frequencies and Percentage)**				
1. In general, would you say your health is	Excellent	Very good	Good	Fair	Poor
	1 (0.6)	8 (4.7)	71 (41.8)	88 (51.8)	2 (1.2)
2. Compared to one year ago, how would you rate your health in general now?	Much better	Somewhat better	About the same	Somewhat worse	Much worse
	1 (0.6)	20 (11.8)	119 (70)	27 (15.9)	3 (1.8)

3.4 Physical Functioning (PF)

The study participants reported on ten questions regarding activities limited by their current health status. The majority (94.1%) reported that vigorous activities—such as running, lifting heavy objects, or participating in strenuous sports—were limited by their health. In contrast, more than one-third of participants reported that basic self-care activities, such as bathing or dressing, were also somewhat limited (Table 3.4).

Table-3.4: The Physical Functioning: Activities Limited by Health Status Among Thalassemia Patient in Kerbala(n=170)

Does your health now limit you in these activities? If so, how much?			
	Yes, limited a lot	Yes, limited a little	No, not limited at all
3. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	46 (27.1)	114 (67)	10 (5.9)
4. Moderate activities, such as moving a table, pushing a vacuum cleaner, cleaning and taking care of one's garden	29 (17.1)	102 (60)	39 (22.9)
5. Lifting or carrying groceries	61 (35.9)	66 (38.8)	43 (25.3)
6. Climbing several flights of stairs	70 (41.2)	69 (40.6)	31 (18.2)
7. Climbing one flight of stairs	45 (26.5)	79 (46.5)	46 (27.1)
8. Bending, kneeling, or stooping	22 (12.9)	100 (58.9)	48 (28.2)
9. Walking more than one kilo meter and half	46 (27.1)	87 (51.1)	37 (21.8)
10. Walking a half kilo meter	29 (17.1)	78 (45.9)	63 (37.1)
11. Walking a hundred meters	37 (21.8)	84 (49.4)	49 (28.8)
12. Bathing or dressing yourself	34 (20)	75 (44.1)	61 (35.9)

3.5 Role Limitations due to Physical Health:

Nearly one third of participants reported difficulties in performing their work or daily activities all or most of the time due to their physical health. The highest proportion of participants (57%) accomplished less than they would like some of the time, while a smaller proportion reported being limited all the time (Table 3.5).

Table-3.5: The Role Limitations Due to Physical Health: Impact on Work and Daily Activities Among Thalassemia Patient in Kerbala(n=170)

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?					
	All the time	**Most** of the time	**Some** of the time	A **little** of the time	**None** of the time
13. Cut down the amount of time you spent on work or other activities	5 (2.9)	55 (32.4)	82 (48.2)	20 (11.8)	8 (4.7)
14. Accomplished less than you would like	3 (1.8)	36 (21.2)	97 (57)	23 (13.5)	11 (6.5)
15. Were limited in the kind of work or other activities	0	55 (32.4)	63 (37.1)	38 (22.4)	14 (8.2)
16. Had difficulty performing the work or other activities (for example, it took extra effort)	3 (1.8)	53 (31.2)	65 (38.2)	35 (20.6)	14 (8.2)

3.6 Role Limitations due to Emotional Problems:

Nearly one third of participants reported difficulties in performing work or daily activities due to emotional problems (e.g., feeling depressed or anxious). Most participants accomplished less than they would like some of the time, while very few reported being limited all of the time (Table 3.6).

Table-3.6: The Role Limitations Due to Emotional Problems: Impact on Work and Daily Activities Among Thalassemia Patient in Kerbala(n=170)

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?					
	All the time	**Most** of the time	**Some** of the time	A **little** of the time	**None** of the time
17. Cut down the amount of time you spent on work or other activities	1 (0.6)	65 (38.2)	68 (40)	25 (14.7)	11 (6.5)
18. Accomplished less than you would like	0	55 (32.4)	66 (38.8)	39 (22.9)	10 (5.9)
19. Did work or activities less carefully than usual	2 (1.2)	54 (31.8)	73 (42.9)	24 (14.1)	17 (10)

3.7 Social Functioning:

The majority of participants reported that their physical or emotional health interfered with normal social activities. Most participants experienced interference moderately or some of the time, while only a small proportion reported no interference (Table 3.7).

Table-3.7: The Social Functioning: Impact of Physical and Emotional Health on Social Activities Among Thalassemia Patient in Kerbala(n=170)

20. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?				
Not at all	Slightly	Moderately	Quite a bit	Extremely
9 (5.3)	41 (24.1)	72 (42.4)	40 (23.5)	8 (4.7)
32. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?				
All of the time	Most of the time	Some of the time	A little of the time	None of the time
3 (1.8)	40 (23.5)	79 (46.5)	36 (21.2)	12 (7.1)

3.8 Bodily Pain:

More than half of the participants reported experiencing moderate to severe bodily pain in the past 4 weeks. Pain also interfered with daily activities for most participants, particularly at a moderate level, while few reported no interference (Table 3.8).

Table-3.8: The Bodily Pain: Intensity and Impact on Daily Activities Among Thalassemia Patient in Kerbala(n=170)

Items in the questionnaire	**Choices**					
21. How much bodily pain have you had during the past 4 weeks?	None	Very mild	Mild	Moderate	Severe	Very severe
	6(3.5)	36(21.2)	36(21.2)	76(44.7)	16(9.4)	0
22. In the past 4 weeks, to what extent did pain interfere with your usual activities (including work outside the home and household tasks)?	Not at all	Slightly	Moderately	Quite a bit	Extremely	
	16(9.4)	53(31.2)	85(50)	16(9.4)	0	

3.9 Vitality and Mental Health:

More than one third of participants reported feeling full of life and regarded themselves as happy most or all of the time. Simultaneously, more than one third reported feeling very nervous or downhearted at some point in the past 4 weeks (Table 3.9).

Table-3.9: The Vitality and Mental Health: Feelings and Energy-Related Responses Among Thalassemia Patient in Kerbala(n=170)

These questions are about how you feel and how things have been with you during the past 4 weeks. How much of the time during the past 4 weeks...					
	All of the time	Most of the time	Some of the time	A little of the time	None of the time
23. Did you feel full of life?	9 (5.3)	67 (39.4)	72 (42.4)	21 (12.4)	1 (0.6)
24. Have you been a very nervous person?	8 (4.7)	59 (34.7)	78 (45.9)	18 (10.6)	7 (4.1)
25. Have you felt so down in the dumps that nothing could cheer you up?	2 (1.2)	61 (35.9)	72 (42.4)	31 (18.2)	4 (2.4)
26. Have you felt calm and peaceful?	15 (8.8)	68 (40)	52 (30.6)	31 (18.2)	4 (2.4)
27. Did you have a lot of energy?	9 (5.3)	61 (35.9)	54 (31.8)	39 (22.9)	7 (4.1)
28. Have you felt downhearted and blue?	7 (4.1)	59 (34.7)	67 (39.4)	27 (15.9)	10 (5.9)
29. Did you feel worn out?	7 (4.1)	55 (32.4)	65 (38.2)	40 (23.5)	3 (1.8)
30. Have you been a happy person?	3 (1.8)	56 (32.9)	68 (40)	37 (21.8)	6 (3.5)
31. Did you feel tired?	9 (5.3)	63 (37.1)	64 (37.6)	26 (15.3)	8 (4.7)

3.10 General Health:

About two thirds of participants reported that they seem to get sick slightly easier than others, while more than half considered their health to be excellent. Participants' perceptions of their health varied, reflecting a mix of confidence and concern regarding their general health (Table 3.10).

Table-3.10: The General Health: Health Perceptions and Beliefs Among Thalassemia Patient in Kerbala(n=170)

How TRUE or FALSE is each of the following statements for you.					
	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
33. I seem to get sick a little easier than other people	18 (10.6)	97 (57.1)	36 (21.1)	16 (9.4)	3 (1.8)
34. I am as healthy as anybody I know	21 (12.4)	62 (36.5)	71 (41.8)	10 (5.9)	6 (3.5)
35. I expect my health to get worse	20 (11.8)	72 (42.4)	58 (34.1)	19 (11.2)	1 (0.6)
36. My health is excellent	23 (13.5)	77 (45.3)	25 (26.5)	21 (12.4)	4 (2.4)

3.11 Body Image and Support Availability: Participants' Perceptions over the Past Two Weeks (WHO_BREF)

The majority of participants reported being able to accept their bodily appearance and receiving adequate support to meet their needs over the past two weeks (Table 3.11).

Table-3.11: The Body Image and Support Availability Participants' Perceptions over the Past Two Weeks Among Thalassemia Patient in Kerbala(n=170)

The following questions ask about how much you have experienced certain things in the last two weeks:					
	Not at all	Slightly	Somewhat	To a great extent	Completely
Are you able to accept your bodily appearance?	20 (11.8)	79 (46.5)	56 (32.9)	14 (8.2)	1 (0.6)
Do you got enough support to meet your needs?	15 (8.8)	64 (37.6)	65 (38.2)	19 (11.2)	7 (4.1)

3.12 Satisfaction with Life Aspects: Sleep, Social Support, and Health Services

Less than half of participants reported dissatisfaction with their sleep. More than one third of participants expressed satisfaction regarding support from family, friends, and the community, as well as access to health services (Table 3.12).

Table-3.12: Satisfaction with Life Aspects Sleep, Social Support, and Health Services Among Thalassemia Patient in Kerbala(n=170)

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last two weeks:					
	Very dissatisfied	Fairly dissatisfied	Neither satisfied nor dissatisfied	satisfied	Very satisfied
How satisfied are you with your sleep?	10 (5.9)	72 (42.4)	55 (32.4)	17 (10)	16 (9.4)
How satisfied are you with the support you get from your family?	5 (2.9)	36 (21.2)	57 (33.5)	55 (32.4)	17 (10)
How satisfied are you with the support you get from your friends?	4 (2.4)	42 (24.7)	51 (30)	56 (32.9)	17 (10)
How satisfied are you with the support you get from the community?	8 (4.7)	36 (21.2)	69 (40.6)	46 (27.1)	11 (6.5)
How satisfied are you with your access to health services?	3 (1.8)	30 (17.6)	75 (44.1)	47 (27.6)	15 (8.8)

The analysis of data revealed that Total (Mean) QOL Score was 49.76±10.61, least score was for General Health and higher score was for social functioning as shown in table 3.13.

Table-3.13: The QOL Scores Across SF-36 Domains Among Thalassemia Patient in Kerbala(n=170)

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**

3.14 The association of Different Domains of QOL with Demographic Characteristics:

The statistical analysis revealed no significant differences in quality of life (QoL) domain scores with respect to age and gender ($p > 0.05$). However, single participants scored significantly higher than married individuals in the domains of Physical Functioning and Role Limitations due to Physical Health ($p < 0.05$).

Regarding educational level, participants with higher academic qualifications exhibited significantly better scores in Social Functioning and Emotional Well-being ($p < 0.05$). Employment status also showed a significant influence, with employed participants scoring higher in Physical Functioning, Physical Role Limitation, and Emotional Role Limitation ($p < 0.05$).

Monthly income was positively associated with QoL domain, where individuals with higher income levels scored significantly better across all domains except General Health ($p < 0.05$), as presented in Table 14.

Additionally, patients whose thalassemia onset occurred at or after six months of age reported significantly higher scores in Bodily Pain and Vitality domains compared to those diagnosed earlier ($p < 0.05$). Blood transfusion frequency also impacted QoL: those receiving transfusions every two weeks scored significantly higher in Social Functioning, Bodily Pain, and Emotional Well-being than those with less frequent transfusions ($p < 0.05$).

Interestingly, patients who were not receiving chelation therapy demonstrated significantly higher scores in General Health, Physical Functioning, Physical Role Limitation, Emotional Role Limitation, Bodily Pain, and Emotional Well-being compared to those undergoing chelation treatment ($p < 0.05$).

Table-3.14: The QOL scores (mean and standard deviation) according to demographic characteristics Among Thalassemia Patient in Kerbala(n=170)

	GH	PF	PRL	RLE	SF	BP	MH	VT
Gender								
Male	47.43± 8.23	48.49± 19.61	47.12± 15.02	46.16± 17.50	52.63± 18.52	50.82± 21.34	50.26± 10.00	51.32± 9.70
Female	46.33± 8.96	51.65± 22.89	51.60± 19.95	51.68± 21.22	50.13± 19.87	50.53± 20.41	48.56± 11.81	50.67± 12.48
Age (years)								
12-19	46.49± 8.47	53.77± 22.87	49.92± 18.32	50.33± 20.83	50.00± 19.97	51.62± 20.01	49.16± 9.26	51.87± 11.47
20 and above	47.10± 8.80	47.31± 19.91	49.33± 17.83	48.30± 18.94	52.29± 18.70	49.87± 21.45	49.46± 12.37	50.20± 11.15
Marital status								
Single	46.33± 9.14	52.05± 22.13	50.28± 19.07	50.88± 20.50	51.04± 20.90	50.47± 21.48	49.51± 11.85	50.28± 11.45
Married	48.55± 6.36	43.95± 19.94*	47.20± 13.61	43.42± 16.00*	51.97± 12.17	51.32± 18.33	48.68± 7.68	53.29± 10.55
Academic qualification								
Illiterate	48.64± 2.34	44.09± 16.10	36.36± 17.19	43.18± 14.82	40.91± 11.31	62.50± 21.65	46.36± 2.34	53.41± 7.59
Primary school	46.35± 8.20	51.85± 22.17	50.39± 18.35	48.80± 20.10	48.65± 18.02	48.99± 18.63	48.33± 9.59	52.03± 9.54
Secondary school	45.58± 10.98	44.42± 16.08	51.44± 13.73	53.85± 20.03	**56.73± 22.70**	48.08± 21.99	49.62± 12.72	45.91± 16.39
College	49.77± 9.32	52.05± 25.10	50.00± 19.48	48.86± 20.13	**63.07± 18.29****	56.25± 26.93	**55.46± 15.96****	50.28± 12.72
Occupation								
Student	47.88± 9.57	54.85± 22.40	51.61± 19.31	54.55± 21.09	54.36± 20.39	50.38± 22.36	51.21± 13.19	49.15± 14.66
Employed	44.77± 8.23	60.00± 27.78	62.22± 26.34	57.96± 30.26	44.89± 22.71	52.84± 18.87	46.14± 4.86	50.28± 8.51
Unemployed	45.56± 9.43	46.78± 19.16	43.75± 12.36	44.26± 11.35	49.17± 20.01	51.11± 22.59	48.33± 11.87	51.11± 7.33
Free business	47.70± 5.35	40.41± 12.27**	45.61± 9.65**	40.54± 11.65**	52.03± 12.33	49.32± 16.91	49.05± 7.62	54.39± 9.18
Income								
Low	46.99± 9.69	47.52± 17.81	45.39± 14.30	47.09± 15.38	49.03± 17.91	48.54± 21.53	48.40± 10.78	48.54± 11.08
Middle	45.71± 7.50	49.39± 25.16	52.17± 21.48	49.66± 23.45	47.45± 17.49	46.68± 15.68	47.25± 5.78	53.06± 10.06
High	48.89± 3.23	68.06± 22.70**	66.67± 16.04**	60.19± 27.65**	74.31± 16.31**	73.61± 13.48**	60.28± 16.58**	59.03± 11.39**
Age of onset of thalassemia								
< 6 months	47.18± 10.81	47.44± 17.20	50.80± 8.98	48.08± 13.17	46.80± 23.77	44.87± 21.41	47.31± 11.46	43.75± 11.38
≥ 6 months	46.72± 7.91	51.07± 22.59	49.24± 19.93	49.56± 21.39	52.58± 17.59	52.39± 20.34*	49.92± 10.88	53.10± 10.38*

Frequency of blood transfusion								
Every 2 weeks	48.01± 6.85	51.87± 22.19	50.75± 16.02	50.0± 18.03	54.52± 18.78	54.52± 22.56	51.69± 12.43	49.25± 11.77
3-4 weeks	45.69± 9.95	48.68± 20.79	48.49± 19.74	48.47± 21.40	48.13± 19.30*	46.98± 18.28*	47.07± 9.04*	52.59± 10.64
History of splenectomy								
Yes	46.33± 7.54	48.90± 17.71	47.19± 15.56	47.17± 17.02	50.92± 18.14	49.08± 18.77	49.17± 9.37	51.20± 11.92
No	47.71± 10.31	52.62± 26.95	53.89± 21.17*	52.87± 23.66	51.84± 21.27	53.48± 23.84	49.59± 13.61	50.51± 10.16
Use of chelation therapy								
Yes	46.95± 8.72	47.82± 19.78	47.56± 15.65	47.02± 17.25	50.99± 17.41	49.34± 20.30	48.54± 10.84	50.91± 11.89
No	45.79± 8.04	69.47± 25.16*	65.79± 26.30*	66.67± 28.87*	53.29± 30.86	61.18± 22.01*	55.53± 10.92*	51.32± 4.46
Do you have a family member with thalassemia								
Yes	46.86± 8.87	50.34± 20.20	47.43± 15.47	47.79± 16.25	51.72± 20.29	49.88± 20.09	49.07± 12.97	48.10± 10.62
No	46.77± 8.32	50.07± 23.43	52.85± 20.95	51.35± 24.12	50.55± 17.73	51.84± 21.84	49.71± 7.32	55.24± 10.99*

GH = General health; PF = Physical functioning; PRL = Physical role limitation; RLE = Role limitation emotional; SF = Social functioning; BP = Bodily pain; MH = Mental health: VT = Vitality.

All values are written in M ± SD. *Significant by t-test, **Significant by ANOVA test.

In regard to association of Total QOL Score with demographic and clinical characteristics of the participants, the analysis of data revealed that only monthly income and the use of chelation therapy were associated with significantly higher Total QOL Score ($p<0.05$) as shown in table 3.15.

Table-3.15: The Association of Total QOL Score with demographic and clinical characteristics Among Thalassemia Patient in Kerbala(n=170)

Variables	**Categories**	**QOL** mean ± SD	**P value**
Gender	Male	49.28±9.47	0.599
	Female	50.14±11.49	
Age (years)	12-19	50.39±10.17	0.479
	20 and above	49.23±10.99	
Marital status	Single	50.11±11.62	0.427
	Married	48.55±5.84	
Academic qualification	Illiterate	46.93±6.74	0.357
	Primary school	49.42±9.08	
	Secondary school	49.45±13.09	
	College	53.22±15.20	
Occupation	Student	51.75±13.72	0.055
	Employed	52.39±10.32	
	Unemployed	47.51±7.50	
	Free business	47.38±5.87	
Income	Low	47.69±9.16	< 0.001**
	Middle	48.92±9.05	
	High	63.88±12.06	
Age of onset of thalassemia	< 6 months	47.03±10.07	0.067
	≥ 6 months	50.57±10.67	
Frequency of blood transfusion	Every 2 months	51.33±11.28	0.060
	3-4 months	48.26±9.77	
History of splenectomy	Yes	48.75±8.37	0.097
	No	51.57±13.64	
Use of chelation therapy	Yes	48.64±10.00	< 0.001*
	No	58.63±11.40	
Family member with thalassemia	Yes	48.90±10.45	0.197
	No	51.05±10.80	

*Significant by t-test, **Significant by ANOVA test.

CHAPTER FOUR

DISSCUSION

4.1 DISSCUSION

Patients with β-thalassemia major (β-TM) require lifelong blood transfusions, which increase the risk of iron overload and related complications **(Musallam et al., 2025)**. Assessing health-related quality of life (HRQoL) provides insight into how chronic treatments affect physical, psychological, and social aspects of patients' lives **(Tarım and Öz, 2022; Premawardhena et al., 2024)**.In the present study conducted in Kerbala, Iraq, the mean total SF-36 QoL score was 49.76 ± 10.61, indicating a moderate level of perceived quality of life, consistent with recent studies in Iran, Egypt, and Saudi Arabia **(Asadi-Pooya et al., 2022; Ezz El-Din et al., 2021; Alzahrani et al., 2022).**

The lowest mean score was found in the General Health domain, whereas Social Functioning recorded the highest. This indicates that, despite receiving regular transfusions and follow-up, patients still perceive considerable health limitations but maintain a fair degree of social connectedness. Similar domain distributions were reported among thalassemia patients in Jordan and Turkey **(Al-Akour et al., 2017; Tarım and Öz, 2022).**

Physical and vitality domains were notably impaired, reflecting chronic anemia, fatigue, and reduced endurance associated with β-TM. Comparable results were found in India and Iran, where physical fatigue was a major contributor to poor QoL **(Khurana et al., 2021; Haghpanah and Karimi, 2020).** The emotional and mental health domains were moderately affected; nearly half of participants reported feeling nervous, sad, or exhausted most of the time. This aligns with evidence showing that thalassemia patients experience persistent psychological distress related to treatment dependency, facial deformities, and social stigma **(Gharaibeh and Barqawi, 2021; Musallam et al., 2023)**. A recent meta-analysis confirmed that the prevalence of depression and anxiety among β-TM patients remains between 40–60% despite medical advancements **(Li et al., 2023).**

Similarly, a study from the northern region of Iraq by **Mikael and Al-Allawi (2018)** assessed the quality of life among children and adolescents with thalassemia in Iraqi Kurdistan. They found significantly reduced HRQoL compared to healthy controls, with the greatest impairment in physical functioning and psychosocial domains. In contrast, the current study conducted in Kerbala—mainly involving adolescents and adults—showed relatively higher scores in social functioning and emotional well-being. This difference may be attributed to the older age of participants in the present study, better social adaptation, and regional differences in healthcare access and psychosocial support services.

Sociodemographic factors significantly influenced QoL variation. Higher income was associated with better scores across all domains, likely reflecting easier access to healthcare and improved living standards **(Pakbaz et al., 2022; Li et al., 2023).** Likewise, higher education levels correlated with better emotional well-being and social functioning, consistent with studies from Lebanon and Egypt **(Kharroubi and Abu Sabeib, 2018; Ezz El-Din et al., 2021).** Employment also played a role, as working patients showed higher physical and emotional domain scores, likely due to enhanced social engagement and self-esteem **(Al-Rawas and Daar, 2015).**

Regarding marital status, single patients scored higher in physical functioning, while married ones scored better in social functioning—possibly reflecting spousal and emotional support. This pattern is consistent with findings from Oman and Lebanon **(Al-Rawas and Daar, 2014; Kharroubi and Abu Sabeib, 2018).**

Interestingly, patients not using chelation therapy reported higher scores in several domains, including General Health and Physical Functioning. This likely represents individuals with milder disease or inconsistent follow-up rather than actual therapeutic benefit. Studies confirm that adherence to chelation therapy, especially modern oral formulations such as film-coated deferasirox, significantly improves HRQoL and reduces iron overload complications **(Scalone et al., 2018; Premawardhena et al., 2024; Chalmers et al., 2016; Shah et al., 2017).**

Frequency of blood transfusions also influenced QoL outcomes. Participants receiving transfusions every two weeks had higher Social Functioning and Vitality scores, likely due to better hemoglobin stability and fewer anemia-related symptoms. These findings are similar to results from studies in Egypt and Iran **(Ezz El-Din et al., 2021; Asadi-Pooya et al., 2022).** Furthermore, complications such as splenectomy, endocrine disorders, and osteoporosis were associated with lower general health scores, comparable to observations from Saudi Arabia and Pakistan **(Alzahrani et al., 2022; Ahmed et al., 2021).** These underline the importance of regular endocrine and metabolic monitoring.

Psychological challenges, including anxiety, low self-esteem, and body image issues, substantially affected QoL. Incorporating mental health counseling and peer-support programs into thalassemia care has been proven effective in improving treatment adherence and emotional well-being **(Eljedi et al., 2019; Gharaibeh and Barqawi, 2021).** Recent psychosocial interventions in Egypt and Lebanon have demonstrated that structured therapy and community engagement significantly enhance HRQoL, especially among adolescents **(Ezz El-Din et al., 2021; Al-Akhras et al., 2021).**34

Overall, this study emphasizes that socioeconomic status, education, employment, treatment adherence, and psychosocial support are critical determinants of QoL among β-TM patients. The findings highlight the importance of adopting a multidisciplinary, patient-centered approach integrating medical, psychological, and social care to optimize outcomes **(Lafta and Mohammed, 2023; Thalassemia International Federation, 2021).**

4.2 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.

CHAPTER FIVE

CONCLUSIONS AND RECOMMNDATIONS

5.1 Conclusions

1. Beta-thalassemia major significantly affects various dimensions of patients' quality of life, especially in general health, energy levels, and physical capabilities.
2. 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
    - 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.

5.2 Recommendations

1. **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.
2. **Enhance Education and Treatment Adherence:**
   Improve patient understanding of their condition and encourage adherence to treatments—particularly iron chelation—through targeted education and support.
3. **Support Social and Economic Inclusion:**
   Promote policies that facilitate employment, flexible education, and reduce stigma to improve social integration and quality of life.
4. **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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Appendix

Appendix 1

استبيان عن جودة الحياة لدى المراهقين و البالغين المصابين بمرض بيتا ثلاسيميا الكبرى في مركز أمراض الدم الوراثية في مدينة كربلاء، ٢٠٢٤

عزيزي المشارك، نقوم بإجراء بحث على مرضى بيتا ثلاسيميا الكبرى من أجل تقييم العوامل التي تؤثر على نوعية الحياة لدى هؤلاء المرضى فيما يتعلق بهذا المرض. سيساعدنا هذا البحث على تحسين حياة المرضى الذين يعانون من هذا المرض في المستقبل. سيكون اسمك مجهولاً في هذا النموذج وسيتم استخدام المعلومات للأغراض العلمية فقط وستظل سرية. نحن نقدر بشدة مساعدتكم في الرد على هذا الاستبيان.

١. العمر بالسنوات: ☐ تاريخ الميلاد: ☐

٢. الجنس: ذكر ☐ أنثى ☐

٣. الحالة الاجتماعية:

أعزب		متزوج	
أرمل/أرملة		مطلق/مطلقة	

٤. المستوى التعليمي:

لا يقرأ ولايكتب		يقرأ ويكتب		الابتدائية	
الثانوية		الكلية		التعليم العالي	

٥. الوضيفة:

طالب		موظف حكومي		موظف قطاع خاص	
غير موضف		اعمال حرة		متقاعد	

٦. الدخل الشهري (دينار عراقي):

أقل من ٥٠٠الف ☐

من ٥٠٠ ألف - مليون ☐

أكثر من مليون ☐

٧ .عمر ظهور الثلاسيميا:

☐

٧ .عمر ظهور الثلاسيميا:

أقل من ٦ أشهر ☐

٦ -١٢ شهرًا ☐

>١٢ شهرًا ☐

٨ .عدد مرات نقل الدم:

كل أسبوعين ☐

كل ٣ أسابيع ☐

كل ٤ أسابيع ☐

٩. استئصال الطحال: نعم ☐

لا ☐

١٠. استخدام علاج طاردات الحديد: نعم ☐ ,لا ☐

١١. نوع طاردات الحديد: ديفيروكسامين أبر (دسفيرال) ☐ ديفراسيروكس حب ☐ ,

ديفيروكسامين مع ديفراسيروكس ☐

١٢. هل لديك أحد أفراد الأسرة مصاب بالثلاسيميا (الأب، الأم،الأخ، الأخت، الابن، الابنة): نعم ☐ ، لا ☐

إذا كانت الإجابة بنعم، فكم عدد أفراد الأسرة المصابين بالثلاسيميا ☐

١٣. أحدث قراءة لمستوى الهيموجلوبين(نسبة الدم): ☐

١٤ .أحدث قراءة لمستوى الفطيريتين(نسبة الحديد):

اقل من ٥٠٠ ☐

من ٥٠٠-٩٩٩ ☐

من ١٠٠٠-١٩٩٩ ☐

اكثر او يساوي ٢٠٠٠ ☐

١٥. ما هي المضاعفات التي تعاني منها بسبب المرض (يمكنك اختيار أكثر من إجابة):

ارتفاع ضغط الدم		مرض السكري		امراض القلب		هشاشة العضام	
قصور الغدة الدرقية		التهاب الكبد الفايروسي نوعB		التهاب الكبد الفايروسي نوعC		اضطرابات نفسية(قلق,اكتئاب وغيرها)	
أخرى (حدد)							

١٦. هل لديك أمراض أخرى (يمكنك اختيار أكثر من إجابة):

أمراض القلب		الجلطة الدماغية		امراض الكلى	
امراض الغدة الدرقية		ارتفاع نسبة الدهون في الدم		مرض السكري	
ارتفاع ضغط الدم		أخرى (حدد)			

الرجاء الإجابة على كل سؤال. قد تبدو بعض الأسئلة مثل غيرها، ولكن كل واحد منها يختلف عن الآخر. يرجى تخصيص الوقت لقراءة كل سؤال والإجابة عليه بعناية من خلال وضع دائرة حول الرقم الذي يمثل إجابتك على أفضل وجه (SF36النسخة المعدلة)

١. بصورة عامة ,كيف ترى حالتك الصحية؟

ممتازة ١	جيدة جدا ٢	جيدة ٣	لا باس بها ٤	سيئة ٥

٢. مقارنة بالعام الماضي، كيف تقيم حالتك الصحية الآن بصورة عامة ؟

أفضل بكثير الآن مما كانت عليه قبل عام ١	أفضل نوعا ما من العام الماضي ٢	تقريبا على ماهي عليه ٣	أسوأ نوعا ما من العام الماضي ٤	أسوأ بكثير مما كانت عليه قبل عام ٥

٣. الأسئلة التالية تتعلق بالأنشطة التي قد تقوم بها خلال يوم عادي. في الوقت الحالي ,الى اي مدى تقيدك او تمنعك حالتك الصحية من ممارسة هذه الأنشطة؟ (ضع دائرة حول رقم واحد في كل سطر)

	نعم، تقيدني كثيرًا	نعم، تقيدني قليلًا	لا تقيدني اطلاقا
أ. ممارسة الأنشطة الشاقة مثل الجري ,حمل الأشياء الثقيلة او مزاولة الانشطة الرياضية المجهدة جدا؟	١	٢	٣
ب. ممارسة الأنشطة متوسطة الجهد، مثل تحريك الطاولة، أو التنضيف بالمكنسة الكهربائية، أو البولينج، أو لعب الجولف؟	١	٢	٣
ج. رفع أو حمل المشتريات من البقالة او السوق او السوبرماركت؟	١	٢	٣
د. صعود الدرج أكثر من طابق؟	١	٢	٣
ج. صعود الدرج طابق واحد فقط؟	١	٢	٣
ح. الانحناء أو الركوع او السجود؟	١	٢	٣
خ. المشي لأكثر من كيلومتر واحد؟	١	٢	٣
د. المشي لمسافة نصف كيلو؟	١	٢	٣
ذ. المشي مسافة ٥٠ متر؟	١	٢	٣
ر. الاستحمام أو ارتداء الملابس بنفسك؟	١	٢	٣

٤. تتعلق البنود التالية (أ,ب,ج,د)بالمشاكل التي يمكن ان تواجهك خلال تأديك لعملك او دراستك او الانشطة اليومية المعتادة نتيجة لصحتك البدنية.خلال الأسابيع الأربعة الماضية، هل تسببت صحتك البدنية في: (ضع دائرة حول رقم واحد على كل سطر)

	كل الوقت	اغلب الوقت	بعض الوقت	قليل من الوقت	لا شيء من الوقت
أ.قللت من الوقت الذي تقضيه في العمل او الدراسة أو اي أنشطة اخرى ؟	١	٢	٣	٤	٥
ب.قللت او لم تقم بالعمل كما تحب ؟	١	٢	٣	٤	٥
ج.تقييدك في أداء نوع معين من الاعمال أو أي أنشطة اخرى؟	١	٢	٣	٤	٥
د.واجهت صعوبة في أداء العمل أو الأنشطة الأخرى؟ (على سبيل المثال، احتجت الى جهد اضافي لتأديتها)	١	٢	٣	٤	٥

٥. تتعلق البنود التالية (أ,ب,ج)بالمشاكل التي يمكن ان تواجهك خلال تأديك لعملك او دراستك او الانشطة اليومية المعتادة نتيجة لحالتك الصحية النفسية(مثلا الشعور بالاكتئاب أو القلق).خلال الأسابيع الأربعة الماضية، هل تسببت حالتك الصحية النفسية في: (ضع دائرة حول رقم واحد على كل سطر)

	في كل الأوقات	في معظم الأوقات	في بعض الاوقات	في قليل من الاوقات	لا شيء من الوقت
أ.التقليل من الوقت الذي تقضيه في العمل او الدراسة أو الأنشطة الأخرى؟	١	٢	٣	٤	٥
ب.لم تقم بالعمل كما تحب؟	١	٢	٣	٤	٥
ج.عدم انجاز العمل او أي انشطة اخرى بعناية وحرص اقل من المعتاد؟	١	٢	٣	٤	٥

٦. خلال الأسابيع الأربعة الماضية، إلى أي مدى تعارضت صحتك الجسدية أوالنفسية مع تأديك لنشاطاتك الاجتماعية المعتادة مع عائلتك او اصدقائك او جيرانك او اي من المناسبات الاجتماعية الاخرى؟ (اختر واحدة)

لم يكن هنالك اي تعارض اطلاقا ١	تعارض قليل ٢	تعارض متوسط ٣	تعارض كبير ٤	تعارض كبير جدا ٥

٧. ما شدة الألم الجسدي الذي عانيت منه خلال الأسابيع الأربعة الماضية؟ (اختر واحدة)

لم يكن هنالك اي ألم ١	ألم خفيف جدا ٢	ألم خفيف ٣	ألم متوسط ٤	ألم شديد ٥	ألم شديد جدا ٦

٨. خلال الأسابيع الأربعة الماضية، الى أي مدى ادى الألم الجسدي الى التعارض مع دراستك او اعمالك المعتادة (سواء داخل المنزل او خارجه)؟ (اختر واحدة)

لم يكن هنالك اي تعارض اطلاقا ١	تعارض قليل ٢	تعارض متوسط ٣	تعارض كبير ٤	تعارض كبير جدا ٥

٩. الاسئلة التالية تتعلق بكيفية شعورك وطبيعة سير الامور معك خلال الاسابيع الاربعة الماضية,الرجاء اعطاء اجابة واحدة لكل سؤال بحيث تكون هذه الاجابة هي الاقرب الى الحالة التي كنت تشعر بها. خلال الاسابيع الاربعة الماضية كم من الوقت:

	في كل الاوقات	في معظم الاوقات	في بعض الاوقات	في قليل من الاوقات	لم أشعر في أي وقت من الاوقات
أ.شعرت بأنك مليئ بالحيوية والنشاط؟	١	٢	٣	٤	٥
ب.كنت شخصا عصبيا جدا؟	١	٢	٣	٤	٥
ج.شعرت بأنك في حالة اكتئاب الى درجة لا شيئ يمنكه ادخال السرور عليك؟	١	٢	٣	٤	٥
د.شعرت بالهدوء والطمأنينة؟	١	٢	٣	٤	٥
هـ.كانت لديك طاقة كبيرة؟	١	٢	٣	٤	٥
و.شعرت بالاحباط واليأس؟	١	٢	٣	٤	٥
ز.شعرت بأنك منهك(استنفذت قواك)؟	١	٢	٣	٤	٥
ح.شعرت بأنك شخص سعيد؟	١	٢	٣	٤	٥
ط.شعرت بأنك تعبان؟	١	٢	٣	٤	٥

١٠. خلال الاسابيع الاربعة الماضية,مامقدار الوقت الذي تعارضت فيه صحتك الجسدية او مشاكلك النفسية مع نشاطاتك الاجتماعية (مثل زيارة الاصدقاء والأقارب وغير ذلك)؟

تعارضت في كل الاوقات	في معظم الاوقات	في بعض الاوقات	في قليل من الاوقات	لم يكن هنالك تعارض في اي وقت من الاوقات

١١. ما مدى صحة أو خطأ كل من العبارات التالية بالنسبة لحالتك الصحية؟ (ضع دائرة حول رقم واحد على كل سطر)

	صحيحة بلا شك	صحيحة غالبا	لا اعلم	خطأ غالبا	خطأ بلا شك
أ.يبدو أنني أصاب بالمرض بشكل أسهل من الآخرين	١	٢	٣	٤	٥
ب.حالتي الصحية مساوية لاي شخص اعرفه	١	٢	٣	٤	٥
ج. أتوقع أن تسوء حالتي الصحية	١	٢	٣	٤	٥
د.حالتي الصحية ممتازة	١	٢	٣	٤	٥

١٢. الأسئلة التالية تستفسرعن مدى تعرضك لأشياء معينة خلال الأسبوعين الماضيين:

	على الاطلاق	قليلا	بدرجة متوسطة	الى حد كبير	بدرجة بالغة
أ.هل أنت قادر على قبول مظهرك الخارجي؟	١	٢	٣	٤	٥
ب. هل لديك الدعم الكافي لتلبية احتياجاتك(مثلا المال, الدعم العاطفي او الاحتياجات الاخرى) ؟	١	٢	٣	٤	٥

١٣. الأسئلة التالية تطلب منك أن تعبر عن مدى رضاك نحو جوانب مختلفة من حياتك خلال الأسبوعين الماضيين:

	غير راض على الاطلاق	غير راض	لا راض ولا غير راض	راض	راض تماما
أ.كم انت راض عن نومك؟	١	٢	٣	٤	٥
ب.كم انت راض عن الدعم الذي تتلقاه من عائلتك؟	١	٢	٣	٤	٥
ج.كم انت راض عن الدعم الذي تتلقاه من أصدقائك؟	١	٢	٣	٤	٥
هـ.كم انت راض عن الدعم الذي تتلقاه من المجتمع؟	١	٢	٣	٤	٥
و.كم انت راض عن الخدمات الصحية المتوفرة لك؟	١	٢	٣	٤	٥

شكرا لكم على صبركم وتعاونكم.....

Appendix 2

Questionnaire on Quality of life among adolescents and adult patients with beta-thalassemia major in hereditary blood diseases center in Karbala City, 2024

Dear Participant, we are conducting a research on beta-thalassemia major patients in order to assess the factors affecting quality of life in these patients regarding this disease. This research will help us improve the lives of patients with this disease in the future. Your name will be anonymous in this form and the information will be used for scientific purpose only and kept confidential. We greatly appreciate your help in responding to this questionnaire.

1. Age in years: ☐ , Date of birth: ☐

2. Gender: male ☐ Female ☐

3. Marital status:

Single		Married	
Widower/widow		Divorced	

4. Educational level:

Illiterate		Read and write		Primary	
Secondary		College		Higher education	

5. Occupation:

Student		Government employee		Private employee	
Unemployed		Free business		Retired	

6. Income per month in Iraqi Dinars:

Less than 500,000 ☐

500,000-1000,000 ☐

≥1000,000 ☐

7. Age of onset of thalassemia: <6 months ☐ , 6-12 months ☐ ,>12 months ☐

8. Frequency of blood transfusion: every 2weeks ☐

, every 3week ☐ , every 4 weeks ☐

9. History of splenectomy: yes ☐ , no ☐

10. The use of chelation therapy: yes ☐ , no ☐

11. Type of chelation: deferoxamine ☐ , frasirox ☐ , combined ☐

12. Do you have a family member with thalassemia (father, mother, brother, sister, son, daughter) :

Yes ☐ , No ☐ if yes then how many family member with thalassemia: ☐

13. latest Hemoglobin level: ☐

14. latest Ferritin level: <500 ☐ ,500-999 ☐ , 1000-1999 ☐ , ≥ 2000 ☐

15. What complications do you have (You can choose more than one answer) :

Hypertension		Diabetes mellitus		Cardiac disease		Osteoporosis	
hypothyrodisim		Hepatitis B infection		Hepatitis C infection		Psychiatric disorder	
Others (specify)							

16.Do you have other diseases (You can choose more than one answer) :

Heart diseases		Stroke		Kidney diseases	
Thyroid diseases		Dyslipidemia		Diabetes mellitus	
Hypertension		Others (specify)			

Please answer every question. Some questions may look like others, but each one is different. Please take the time to read and answer each question carefully by circling the number that best represents your response.(**Modified SF36 questionnaire and some questions derived from WHO QOL questionnaire)**

1. In general, would you say your health is?

Excellent (1)	Very Good (2)	Good (3)	Fair (4)	Poor (5)

2. Compared to one year ago, how would you rate your health in general now?

Much better now than one year ago (1)	Somewhat better now than one year ago (2)	About the same as one year ago (3)	Somewhat worse now than one year ago (4)	Much worse now than one year ago (5)

3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much: (circle one number on each line)

	Yes, Limited A Lot	Yes, Limited A Little	No, Not Limited At All
A. **Vigorous activities**, such as running, lifting heavy objects participating in strenuous sports	1	2	3
B. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
C. Lifting or carrying groceries	1	2	3
D. Climbing **several** flights of stairs	1	2	3
E. Climbing **one** flight of stairs	1	2	3
F. Bending, kneeling, or stooping	1	2	3
G. Walking **more than a mile**	1	2	3
H. Walking **several hundred yards**	1	2	3
I. Walking **one hundred yards**	1	2	3
J. Bathing or dressing yourself	1	2	3

4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health? (Circle one number on each line)

	All the time	**Most** of the time	**Some** of the time	A **little** of the time	**None** of the time
A. Cut down on the **amount of time** you spend on work or other activities	1	2	3	4	5
B. **Accomplished less** than you would like	1	2	3	4	5
C. Were limited in the **kind** of work or other activities	1	2	3	4	5
D. Had **difficulty** performing the work or other activities (for example, it took extra effort)	1	2	3	4	5

5. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)? (Circle one number on each line)

	All the time	**Most** of the time	**Some** of the time	**A little** of the time	**None** of the time
A. Cut down on the **amount of time** you spend on work or other activities	1	2	3	4	5
B. **Accomplished less** than you would like	1	2	3	4	5
C. Did work or activities **less carefully than usual**	1	2	3	4	5

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your social activities with family, friends, neighbors, or groups? (Circle one)

Not at all (1)	Slightly (2)	Moderately (3)	Quite a bit (4)	Extremely (5)

7. How much bodily pain have you had during the past 4 weeks? (Circle one)

over the last two weeks.:

	Very dissatisfied	Fairly dissatisfied	Neither satisfied nor dissatisfied	satisfied	Very satisfied
How satisfied are you with your sleep?	1	2	3	4	5
How satisfied are you with the support you get from your family?	1	2	3	4	5
How satisfied are you with the support you get from your friends ?	1	2	3	4	5
How satisfied are you with the support you get from the community ?	1	2	3	4	5
How satisfied are you with your access to health services?	1	2	3	4	5

We have completed our interview. Thank you for your patience and cooperation.

Scoring Instructions for the 36-Item Short Form Survey (SF-36):

Table-1: Step 1: Recoding Items

Item numbers	Change original response category	To recoded value of:
1, 2, 20, 22, 23, 26, 27, 30, 34, 36	1 →	100
	2 →	75
	3 →	50
	4 →	25
	5 →	0
21	1 →	100
	2 →	80
	3 →	60
	4 →	40
	5 →	20
	6 →	0
3, 4, 5, 6, 7, 8, 9, 10, 11, 12	1 →	0
	2 →	50
	3 →	100
13, 14, 15, 16, 17, 18, 19, 24, 25, 28, 29, 31, 32, 33, 35	1 →	0
	2 →	25
	3 →	50
	4 →	75
	5 →	100

Table-2: Step 2: Averaging Items to Form Scales

Scale	Number of items	After recoding per Table 1, average the following items
Physical functioning	10	3 4 5 6 7 8 9 10 11 12
Role limitations due to physical health	4	13 14 15 16
Role limitations due to emotional problems	3	17 18 19
Energy/fatigue	4	23 27 29 31
Emotional well-being	5	24 25 26 28 30
Social functioning	2	20 32
Pain	2	21 22
General health	5	1 33 34 35 36

الخلاصة

الخلفية:

الثلاسيميا الكبرى (β-TM) هي اضطراب دموي وراثي مزمن يتطلب نقل دم دوري مدى الحياة بالإضافة إلى العلاج بطاردات الحديد، مما يؤثر بشكل كبير على جودة حياة المرضى، لا سيما في البيئات ذات الموارد المحدودة.

هدف البحث:

تهدف هذه الدراسة إلى تقييم جودة الحياة المرتبطة بالصحة (HRQoL) لدى المرضى المراهقين والبالغين المصابين بالبيتا ثلاسيميا الكبرى في محافظة كربلاء، العراق، وتحليل العوامل السريرية والديموغرافية المرتبطة بها.

طرق البحث:

تم إجراء دراسة مقطعية في مركز الأمراض الدموية الوراثية في كربلاء خلال الفترة من عام 2024 إلى 2025. شملت الدراسة 170 مريضًا من عمر 12 سنة فما فوق. جُمعت البيانات باستخدام النسخة العربية من استبيانSF-36 ، بالإضافة إلى عناصر مختارة من استبيان .WHOQOL-BREF وتم تحليل البيانات باستخدام البرنامج الإحصائي SPSS الإصدار 23.

النتائج:

بلغ متوسط الدرجة الكلية لجودة الحياة 49.76±10.61. سجل مجال الأداء الاجتماعي أعلى الدرجات، بينما كان مجال الصحة العامة هو الأدنى. وُجد أن جودة الحياة كانت أفضل لدى المرضى ذوي الدخل الأعلى، المستوى التعليمي العالي، أولئك الذين لديهم عمل، والذين بدأ ظهور المرض لديهم في سن متأخرة، بالإضافة إلى الذين يتلقون عمليات نقل دم منتظمة. ومن المثير للاهتمام أن المرضى الذين لا يستخدمون علاج طاردات الحديد أبلغوا عن درجات أعلى في عدة مجالات.

الاستنتاجات:

تتأثر جودة الحياة لدى مرضى الثلاسيميا الكبرى بشكل ملحوظ بالعوامل الاجتماعية والسريرية. لذا فإن توفير رعاية شاملة متعددة التخصصات، مع التركيز على الصحة النفسية والاندماج الاجتماعي، يُعد أمرًا ضروريًا لتحسين رفاهية المرضى بشكل عام.

وزارة التعليم العالي والبحث
العلمي
جامعة كربلاء
كلية الطب
قسم طب الأسرة والمجتمع

جودة الحياة لدى المراهقين والبالغين المصابين بمرض بيتا ثلاسيميا الكبرى في مركز أمراض الدم الوراثية في مدينة كربلاء 2024

مقدمة إلى مجلس كلية الطب – جامعة كربلاء كجزء من متطلبات الحصول على دبلوم عالٍ (سنتين تقويميتين) في طب الأسرة.

اعداد:

رسل عامر حمودي

بكالوريوس الطب والجراحة العامة

المشرفين على الدراسة

د. شهرزاد شمخي الجبوري

بورد طب المجتمع

د. ايناس مؤيد محمد علي

بورد طب الاطفال

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