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| RESEARCH ARTICLE

Quality of Life and Its Determinants among Patients with β-Thalassemia Major in a Resource-Limited Setting

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| ABSTRACT

Background: β-thalassemia major is a chronic inherited blood disorder that imposes substantial physical, psychological, and social burdens on affected individuals. Beyond survival, quality of life has emerged as a critical outcome, particularly in resource-limited settings where healthcare, psychosocial support, and living conditions are constrained. Main Aim: To assess quality of life and identify its key determinants among patients with β-thalassemia major in a resource-limited setting. Methods: A descriptive cross-sectional study was conducted among 50 patients with β-thalassemia major receiving care at governmental thalassemia centers in the Gaza Strip. Data were collected using a structured questionnaire covering sociodemographic and clinical characteristics, and the World Health Organization Quality of Life–Brief version (WHOQOL-BREF). Descriptive and inferential statistical analyses were performed to examine quality of life domains and associated factors. Findings: Participants demonstrated a moderate overall quality of life. Physical and psychological domains were the most affected, reflecting fatigue, emotional distress, and treatment-related burden. Social relationships showed comparatively better scores, while environmental quality of life was limited by financial constraints, transportation, and access to resources. Younger patients reported relatively higher quality of life than older participants. Conclusion: Patients with β-thalassemia major experience multidimensional challenges that extend beyond clinical symptoms. Routine assessment of quality of life is essential to inform holistic, patient-centered care and address physical, psychological, social, and environmental needs in resource-limited settings.

| KEYWORDS

β-thalassemia major; Quality of life; WHOQOL-BREF; Resource-limited settings

| ARTICLE INFORMATION

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1. Introduction

β-thalassemia major (β-TM) is a severe inherited hemolytic anemia and represents a major public health problem, particularly in Mediterranean countries, the Middle East, Southeast Asia, and other resource-limited regions where consanguineous marriage is common (Baraz et al., 2016; Masih et al., 2023). The disorder is characterized by a marked reduction or complete absence of beta-globin chain synthesis, resulting in chronic anemia that manifests early in childhood and requires lifelong medical management (Modell & Darlison, 2008). Patients with β-TM typically depend on regular blood transfusions and iron chelation therapy to survive, beginning in infancy and continuing throughout life (Rachmilewitz & Giardina, 2011).

Despite significant advances in the clinical management of β-TM that have reduced morbidity and mortality, the disease continues to exert profound effects on multiple aspects of patients' lives (Caocci et al., 2012). Chronic anemia and iron overload contribute to a wide range of complications, including cardiomyopathy, liver dysfunction, endocrine abnormalities, delayed growth and

puberty, skeletal deformities, and increased susceptibility to infections (Benites et al., 2019; Paul et al., 2019). Cardiac involvement remains the leading cause of mortality among patients with β-TM, underscoring the long-term burden of the disease (Taher et al., 2018). These complications, together with frequent hospital visits and treatment-related adverse effects, significantly disrupt daily functioning and social participation.

Quality of life (QoL) has therefore emerged as a critical outcome in the care of individuals with β-TM. The World Health Organization defines QoL as individuals' perception of their position in life within the context of their culture, value systems, goals, expectations, and concerns (WHO, 2012). For patients with chronic conditions such as β-TM, survival alone is no longer sufficient; psychological well-being, social functioning, and overall life satisfaction are equally important (Bahall & Bailey, 2022). Previous studies have demonstrated that patients with β-TM experience significantly lower QoL across physical, emotional, social, and psychological domains compared with healthy populations (Hakeem et al., 2018; Yasmeen & Hasnain, 2018; Alzahrani et al., 2017).

In resource-limited settings, the impact of β-TM on QoL is further exacerbated by constrained health systems, shortages of essential medications, and limited psychosocial support (Vichinsky et al., 2014; Borgna-Pignatti et al., 2014). In the Gaza Strip, patients with β-TM face additional challenges related to medication shortages and interruptions in care, which may lead to disease complications and functional disability (Ministry of Health reports). Despite these challenges, empirical evidence examining QoL and its determinants among β-TM patients in Palestine remains scarce. Assessing QoL and identifying its key determinants in this context is essential to inform patient-centered interventions and guide health policy and planning in resource-constrained settings.

2. Methods

2.1 Study Design, Setting, and Sample

A cross-sectional study design was conducted to evaluate quality of life and its determinants among patients with β-thalassemia major (β-TM) in the Gaza Strip. This design was selected to assess baseline quality of life and examine associated factors in a real-world, resource-limited clinical setting where randomized controlled trials are difficult to implement. The study was conducted in governmental thalassemia centers affiliated with the Ministry of Health (MoH) in the Gaza Strip, Palestine. These centers provide regular blood transfusion services and follow-up care for patients diagnosed with β-thalassemia major. According to MoH records, Gaza Strip hosts a substantial proportion of thalassemia patients in the Palestinian territories, making it a suitable setting for assessing quality of life in this population. The study population consisted of patients diagnosed with β-thalassemia major who were registered and receiving care at MoH thalassemia centers in Gaza Strip. Eligible participants included adolescents and adults with confirmed β-TM diagnosis who were dependent on regular blood transfusions. Patients with severe cognitive impairment or those who were critically ill at the time of data collection were excluded. A convenience sampling technique was used to recruit participants who met the inclusion criteria and consented to participate in the study.

2.2 Data Collection Tool and Procedure

Data were collected using a structured questionnaire composed of two main parts. The first part included socio-demographic and clinical characteristics, such as age, gender, educational level, employment status, disease duration, frequency of blood transfusion, and presence of disease-related complications. The second part assessed quality of life using the World Health Organization Quality of Life Brief version (WHOQOL-BREF), a validated instrument that measures QoL across four domains: physical health, psychological health, social relationships, and environment. Quality of life was defined according to the World Health Organization as individuals' perception of their position in life in relation to their culture, goals, expectations, and concerns (WHO, 2012). Data were collected through face-to-face interviews conducted by the researcher during patients' scheduled visits for blood transfusion. Participants completed the questionnaire.

2.3 Data Analysis and Ethical Considerations

Data were coded and analyzed using statistical software. Descriptive statistics were used to summarize socio-demographic characteristics and QoL domain scores. Inferential statistical tests were applied to identify factors associated with quality of life among patients with β-TM. Statistical significance was set at $p < 0.05$. Ethical approval for the study was obtained from the relevant institutional review board and the Ministry of Health in Gaza Strip. Participation was voluntary, and informed consent was obtained from all participants prior to data collection. Confidentiality and anonymity were strictly maintained by using coded data, and participants were assured of their right to withdraw from the study at any time without consequences.

3. Results

The study included 50 patients with β-thalassemia major receiving care in the Gaza Strip. Participants' ages ranged from 16 to 30 years, with a mean age of 21.74 ± 3.45 years. Slightly more than half of the participants (58%, n = 29) were older than 20 years, while 42% (n = 21) were aged 20 years or younger. Males constituted 56% (n = 28) of the sample, and females 44% (n = 22). Regarding educational attainment, 60% (n = 30) of participants had completed secondary education or less, whereas 40% (n = 20)

had university-level education. Only 26% (n = 13) of participants were employed, while the majority (74%, n = 37) were not working, indicating substantial socioeconomic vulnerability among patients with β-thalassemia major.

Table 1. Sociodemographic Characteristics of Participants (n = 50)

Variable	Category	n (%)
Age group	≤20 years	21 (42.0)
	>20 years	29 (58.0)
Gender	Male	28 (56.0)
	Female	22 (44.0)
Education	Secondary or less	30 (60.0)
	University	20 (40.0)
Employment status	Working	13 (26.0)
	Not working	37 (74.0)

At baseline, participants' perceived quality of life was generally moderate. More than half of participants (52.0%) rated their quality of life as "somehow," while 24.0% rated it as "bad" and 18.0% as "good." The mean overall QoL score was 2.82 ± 0.80, corresponding to 56.4%, indicating a moderate level of quality of life. Satisfaction with health showed a similar pattern. The largest proportion of participants (40.0%) reported being unsatisfied with their health, followed by 32.0% who reported being satisfied. The mean satisfaction with health score was 2.84 ± 0.93 (56.8%), reflecting moderate perceived health status.

Table 2. Overall Quality of Life and Satisfaction with Health

Variable	Mean ± SD	%
Overall quality of life	2.82 ± 0.80	56.4
Satisfaction with health	2.84 ± 0.93	56.8

The physical health domain demonstrated a moderate level of quality of life, with a total mean score of 2.65 ± 0.56. Participants reported limitations related to energy levels, sleep satisfaction, work capacity, and dependence on medical treatment. Fatigue and reduced ability to perform daily activities were commonly reported, reflecting the physical burden associated with β-thalassemia major. Psychological health scores indicated a moderate level of well-being, with a total mean score of 2.83 ± 0.54. Participants reported challenges related to enjoyment of life, self-satisfaction, concentration, and negative emotions such as anxiety and low mood. Concerns about bodily appearance and emotional distress were evident among a considerable proportion of participants. The social relationships domain showed a relatively better level of quality of life compared to other domains, with a mean score of 3.00 ± 0.74. Participants generally reported moderate satisfaction with personal relationships and social support. However, satisfaction with sexual life was notably lower, indicating an important area of psychosocial concern.

Environmental health was rated at a moderate level, with a total mean score of 2.66 ± 0.55. Participants reported limitations related to financial resources, access to leisure activities, transportation, and perceptions of safety. Access to health services was rated moderately, reflecting the constraints of a resource-limited setting.

Table 3. Quality of Life Domain Scores (WHOQOL-BREF)

Domain	Mean ± SD
Physical health	2.65 ± 0.56
Psychological health	2.83 ± 0.54
Social relationships	3.00 ± 0.74
Environmental health	2.66 ± 0.55
Overall QoL	2.75 ± 0.44

Analysis of baseline data showed no statistically significant differences in overall quality of life across gender, educational level, or employment status. However, younger participants (≤20 years) tended to report higher mean scores in physical health, environmental health, and overall QoL compared with older participants, although these differences were modest.

4. Discussion

This study assessed QoL and its determinants among patients with β-thalassemia major in a resource-limited setting in the Gaza Strip. The findings indicate that patients experience an overall moderate level of quality of life, with variations across physical, psychological, social, and environmental domains. These results reinforce the understanding that β-thalassemia major is not only a life-threatening hematological condition but also a chronic illness with profound multidimensional consequences affecting patients' daily lives (Rachmilewitz & Giardina, 2011; Taher et al., 2018).

The physical health domain emerged as one of the most affected aspects of quality of life. Participants reported limitations related to energy levels, sleep quality, work capacity, and dependence on medical treatment. These findings are consistent with previous studies demonstrating that chronic anemia, iron overload, and transfusion-related complications significantly impair physical functioning among patients with β-thalassemia major (Benites et al., 2019; Paul et al., 2019). Similar reductions in physical QoL have been reported in studies from Egypt, Pakistan, and other low- and middle-income countries, highlighting the persistent physical burden associated with long-term disease management (Hakeem et al., 2018; Yasmeen & Hasnain, 2018).

The psychological health domain also reflected a moderate level of quality of life, with participants reporting emotional distress, reduced enjoyment of life, and negative feelings such as anxiety and low mood. These findings align with existing evidence indicating that patients with β-thalassemia major are vulnerable to psychological challenges due to lifelong dependency on treatment, uncertainty about disease progression, body image concerns, and fear of complications (Bahall & Bailey, 2022). Previous studies have similarly documented elevated levels of depression, anxiety, and reduced self-esteem among this population, underscoring the importance of psychological well-being as a core component of QoL (Hakeem et al., 2018; Alzahrani et al., 2017).

In contrast, the social relationships domain demonstrated relatively better scores compared with other domains. This may reflect the role of strong family ties and social support systems, which are characteristic of collectivist cultures and may buffer the negative effects of chronic illness (Ansari et al., 2014). Nevertheless, lower satisfaction with sexual life was evident, consistent with reports that delayed puberty, fertility concerns, and cultural sensitivities negatively influence intimate relationships among patients with β-thalassemia major (Ansari et al., 2014; Yasmeen & Hasnain, 2018).

The environmental domain showed moderate quality of life, with notable limitations related to financial resources, leisure opportunities, transportation, and perceptions of safety. These findings are particularly relevant in resource-limited and conflict-affected settings such as the Gaza Strip, where economic hardship, restricted mobility, and health system constraints may amplify the impact of chronic disease (Vichinsky et al., 2014; Borgna-Pignatti et al., 2014). Moderate satisfaction with access to health services suggests that while essential care is available, broader environmental and socioeconomic challenges continue to shape patients' lived experiences.

Regarding determinants of quality of life, younger participants tended to report higher QoL scores than older patients, a pattern observed in previous research and likely reflecting cumulative disease burden and progressive complications over time (Hakeem

et al., 2018). The absence of significant differences by gender, education, or employment status suggests that the impact of β-thalassemia major on quality of life may be pervasive across sociodemographic groups in this setting.

Overall, the findings highlight the need for comprehensive, patient-centered approaches that address physical symptoms, psychological distress, social concerns, and environmental barriers. Routine assessment of quality of life using standardized tools such as the WHOQOL-BREF can provide valuable insights to guide holistic care planning and improve the well-being of patients with β-thalassemia major in resource-limited settings (WHO, 2012).

5. Conclusion

This study provides important insights into the quality of life of patients with β-thalassemia major in a resource-limited setting. The findings demonstrate that patients experience a moderate level of quality of life, with physical and psychological domains being particularly affected, alongside notable challenges in environmental and social aspects of daily living. These results highlight that the burden of β-thalassemia major extends beyond clinical symptoms to encompass emotional well-being, social functioning, and environmental constraints. Incorporating routine quality of life assessment into thalassemia care can support a more holistic understanding of patients' needs. Addressing multidimensional quality of life concerns is essential to improving overall well-being and ensuring patient-centered care for individuals living with β-thalassemia major.

6. Implications for Future Research

Future research should adopt longitudinal and mixed-methods designs to explore changes in quality of life over time among patients with β-thalassemia major and to better understand the lived experiences underlying quantitative findings. Studies with larger and more diverse samples across different regions are needed to enhance generalizability and to examine contextual influences on quality of life. Further investigation into psychosocial, economic, and health system–related determinants is warranted, particularly in resource-limited and conflict-affected settings. In addition, future research should assess the impact of integrated psychosocial support, patient education, and community-based interventions on QoL outcomes. Incorporating caregivers' perspectives may also provide valuable insights into family dynamics and support needs, informing comprehensive and culturally appropriate care strategies.

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