

Article type:
Original Research

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Article history:

Received 28 July 2024

Revised 22 Oct 2024

Accepted 28 Oct 2024

Published online 26 Feb 2025

How to cite this article:

Toama Abood, H., & Hasan, A. M. (2025). Physical and Psychological Aspects of School-Age Children with Major Thalassaemia. *International Journal of Body, Mind and Culture*, 12(2), 129-136.



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Introduction

Thalassemia, a hereditary blood disorder, is among the most common genetic diseases worldwide, characterized by defects in hemoglobin production, leading to ineffective erythropoiesis and chronic anemia (Musallam et al., 2021). This disorder is classified into transfusion-dependent thalassemia (TDT) and non-transfusion-dependent thalassemia (NTDT), with beta-thalassemia major being the most severe form, requiring lifelong blood transfusions and iron chelation therapy

Physical and Psychological Aspects of School-Age Children with Major Thalassaemia

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ABSTRACT

Objective: This study aims to assess the quality of life (QoL) in the physical and psychological domains among school-age children with major thalassemia compared to healthy peers. Additionally, it seeks to identify differences in QoL between these two groups.

Methods and Materials: Data collection occurred between February 12, 2024, and April 15, 2024. A questionnaire and individual interviews were employed to gather data from participants at a hematology center and a hospital school unit. The same questionnaire was administered to both groups—thalassemia patients and healthy controls—under identical conditions to ensure consistency.

Findings: The findings revealed that in the physical domain, children with thalassemia were significantly less likely to achieve superior QoL scores compared to controls, with 7 (14%) versus 39 (78%), respectively ($p < .001$). In the psychological domain, the frequency of good QoL levels was lower among thalassemia patients compared to controls, at 2 (4%) versus 10 (20%), respectively. Conversely, poor QoL levels were more prevalent in the thalassemia group compared to controls, at 10% versus 4%, respectively ($p = .030$).

Conclusion: Significant disparities in QoL exist between school-age children with major thalassemia and their healthy peers, particularly in physical and psychological domains. Further research, continuous monitoring, and support from governmental, familial, and societal entities, including schools, are imperative to prevent further deterioration and enhance the well-being of affected children.

Keywords: Quality of Life, Major Thalassaemia, Healthy School-Age Children.

(Al-Salehe et al., 2015; Musallam et al., 2021). Advances in management have significantly improved survival; however, the quality of life (QoL) of affected individuals remains a critical concern.

Beta-thalassemia major imposes a substantial burden on physical and psychological health. Growth retardation, delayed puberty, and diminished physical stamina are common due to chronic anemia, iron overload, and associated complications (Al-Salehe et al., 2015; Baker et al., 2013). Psychological distress, including

depression, anxiety, and low self-esteem, is prevalent among children with thalassemia, further exacerbated by societal stigma and frequent medical interventions (Atia et al., 2021; Jabbarifard et al., 2019). Affected children often face significant disruptions in their daily lives, including challenges in academic performance and social interactions, leading to compromised overall well-being (Haghshenas, 2019; Hamdy et al., 2021).

Health-related quality of life (HRQoL) is a multidimensional construct that encompasses physical, psychological, and social domains of health as perceived by individuals (Shen et al., 2024; Türen et al., 2024; Uddin, 2024). HRQoL assessment is particularly critical in chronic illnesses like thalassemia, where disease-related complications and treatment regimens significantly influence patients' well-being (Tinu, 2024; Türen et al., 2024; Uddin, 2024). Studies have consistently demonstrated that children with beta-thalassemia major have lower HRQoL scores compared to their healthy peers, particularly in physical and psychological domains (Cheuk et al., 2008; Ismail et al., 2006; Ismail et al., 2018).

Globally, the prevalence of thalassemia varies, with regions like the Mediterranean, Middle East, and Southeast Asia being most affected due to higher carrier rates (Khodaei et al., 2013; Mettananda & Higgs, 2018). In Iran, the frequency of beta-thalassemia major is notably high, with significant regional variations attributed to consanguineous marriages and genetic predisposition (Khodaei et al., 2013). Despite advances in genetic screening and public health initiatives, the disease continues to pose a substantial public health challenge.

The physical complications of beta-thalassemia major are well-documented. Chronic anemia and iron overload can lead to severe complications, including cardiac, hepatic, and endocrine dysfunctions, which impair physical health and reduce life expectancy (Al-Salehe et al., 2015; Hamdy et al., 2021). Growth impairment and delayed sexual maturation are particularly concerning in pediatric patients, affecting self-image and social acceptance (Al-Salehe et al., 2015; Baker et al., 2013). Moreover, reduced physical activity levels and frequent hospitalizations further limit participation in age-appropriate activities, adversely affecting physical QoL (Hossain et al., 2023; Siddiqui et al., 2014).

Psychological challenges are equally significant. Children with thalassemia often experience feelings of

sadness, loneliness, and anger, contributing to a diminished psychological QoL (Jabbarifard et al., 2019; Okati et al., 2020). The chronic nature of the disease, coupled with frequent medical treatments, contributes to heightened stress and anxiety among these children and their families (Haghshenas, 2019; Kiani et al., 2019). Interventions such as cognitive-behavioral therapy and acceptance and commitment therapy have shown promise in improving psychological well-being and resilience in patients with beta-thalassemia (Khosravani Shayan et al., 2020; Kiani et al., 2019).

The current study aims to evaluate the QoL in school-age children with beta-thalassemia major in both physical and psychological domains and compare their outcomes with healthy peers. By employing a validated QoL instrument, the study seeks to identify specific areas of concern that can inform targeted interventions to improve the overall well-being of affected children (Atia et al., 2021; Mutsher & D, 2011). Additionally, the study underscores the need for integrated care approaches that address not only the medical but also the psychosocial needs of these children (Cheuk et al., 2008; Georgakouli et al., 2020).

This research builds on existing literature to highlight the disparities in QoL between children with beta-thalassemia and their healthy counterparts. It draws on findings from studies conducted in similar populations, such as those in Bangladesh, Egypt, and Iran, to contextualize the challenges faced by children with thalassemia in the Karbala Governorate (Hamdy et al., 2021; Hossain et al., 2023; Khodaei et al., 2013).

By identifying specific areas where QoL is most affected, the study aims to contribute to the development of comprehensive care strategies that enhance the physical and psychological well-being of these vulnerable children. In conclusion, beta-thalassemia major is a complex disorder with profound implications for QoL. While medical advancements have improved survival rates, addressing the holistic needs of affected children remains a priority. This study seeks to bridge the gap in understanding by providing a comprehensive evaluation of QoL in children with beta-thalassemia major, thereby informing future research and intervention strategies.

Methods and Materials

Study Design and Participants

This case-control study was conducted to compare the quality of life (QoL) between school-age children with major thalassemia and healthy controls in the Karbala Governorate. Data collection occurred from February 12, 2024, to April 15, 2024.

The study utilized a purposive (non-probability) sampling method, dividing participants into two categories:

1. **Thalassemia Group:** This group consisted of 50 school-age children of both sexes who were clinically diagnosed with beta-thalassemia major or intermediate. Participants were selected from patient records at the Center for Genetic Blood Diseases and were required to have a scheduled visit to the center during the study period.
2. **Control Group:** This group included 50 healthy school-age children of both sexes.

The study protocol was approved by the Local Research Ethics Committee of the College of Nursing, Babylon University. Further approvals were obtained from the Ministry of Health, Karbala Health Directorate, and Karbala Children's Teaching Hospital, Center for Genetic Blood Diseases. Informed consent was obtained from all participants or their legal guardians, ensuring adherence to ethical standards and the protection of participants' rights.

Data Collection Tools

A global QoL survey adapted from Siddiqui et al. (2014) was used in this study. The questionnaire was modified based on expert feedback and a thorough review of relevant literature to ensure its suitability for achieving the study's objectives.

A draft version of the questionnaire was reviewed by fifteen specialists with over five years of experience, including faculty members from nursing and medical colleges at Al-Qadisiya University, University of Babylon (40%), University of Baghdad (25%), University of Kufa (13%), and Kufa Medical University College of Medicine

(13%). Feedback from these experts was incorporated into the final version.

The questionnaire consisted of two main parts:

- **Part I: Demographic Characteristics:** This section gathered information about the child, including gender and educational level.
- **Part II:**
 1. **Physical Aspect:** This section included three questions addressing physical weakness, ability to participate in sports, and energy levels.
 2. **Psychological Aspect:** This section included four items related to emotional well-being, focusing on sadness, anger, loneliness, and joy.

Data were collected from February 12, 2024, to April 15, 2024, through individual interviews and the administration of the questionnaire. Participants from the thalassemia group were interviewed at the hematology center, while healthy controls were interviewed at a hospital-based school unit. Each interview lasted approximately 25–35 minutes, and the same questionnaire was used across groups to maintain consistency.

Data analysis

Data analysis was conducted using IBM SPSS for Windows, Version 26.0. Statistical comparisons between groups were made using chi-squared tests, Fisher's exact test, and independent-samples t-tests. A p-value of less than .05 was considered statistically significant.

Findings and Results

The data in [Table 1](#) demonstrates significant differences in the physical quality of life (QoL) between children with thalassemia and healthy controls. Children with thalassemia were significantly more likely to feel weak always (24%) compared to controls (4%), with a highly significant difference ($p < .001$). Similarly, thalassemia patients were more likely to report rarely or never participating in sports (4% vs. 36% in controls, $p < .001$).

Table 1

Comparison of Responses of Thalassemia and Control Groups Regarding Physical Aspect of QoL

Item		Groups				P. value*
		Thalassemia (n=50)		Control (n=50)		
		No	%	No	%	
Feel weaker	Always	12	24.0	2	4.0	<0.001 HS
	Often	16	32.0	1	2.0	
	Sometime	17	34.0	6	12.0	
	Rarely	4	8.0	27	54.0	
	Never	1	2.0	14	28.0	
Cannot participate in sports	Always	8	16.0	1	2.0	<0.001 HS
	Often	2	4.0	0	0.0	
	Sometime	14	28.0	8	16.0	
	Rarely	24	48.0	23	46.0	
	Never	2	4.0	18	36.0	
Feel energetic	Never	0	0.0	2	4.0	0.003 HS
	Rarely	10	20.0	5	10.0	
	Sometimes	27	54.0	14	28.0	
	Often	12	24.0	20	40.0	
	Always	1	2.0	9	18.0	

* Fisher's exact test was used to every comparison.

HS: highly significant

When assessing energy levels, only 2% of children with thalassemia reported always feeling energetic,

compared to 18% in the control group. This difference was also statistically significant ($p = .003$).

Table 2

Levels of Physical Aspect QoL in Thalassemia and Control Groups

Physical aspect	Groups				P.value*
	Thalassemia (n=50)		Control (n=50)		
	No.	%	No.	%	
Alright (11-15)	7	14.0	39	78.0	< 0.001 HS
Just (6-10)	40	80.0	10	20.0	
Sadly (<5)	3	6.0	1	2.0	

* Use the Fisher exact test as a comparison measure.

HS: highly significant

Table 2 reveals that children with thalassemia were significantly less likely to achieve a high QoL score in the physical domain compared to controls (14% vs. 78%, respectively, $p < .001$). Most children with thalassemia

(80%) fell into the "just" category, compared to only 20% of controls. Additionally, a greater proportion of thalassemia patients reported poor physical QoL (6%) compared to controls (2%).

Table 3

Comparison of Responses Regarding Psychological Aspect of QoL

Item	Groups		P. value*
	Thalassemia (n=50)	Control (n=50)	

		No	%	No	%	
Feel sad	Always	12	24.0	8	16.0	0.002 HS
	Often	15	30.0	8	16.0	
	Sometime	19	38.0	16	32.0	
	Rarely	1	2.0	16	32.0	
	Never	3	6.0	2	4.0	
Feel angry/ irritated	Always	6	12.0	7	14.0	0.559 NS
	Often	10	20.0	7	14.0	
	Sometime	24	48.0	21	42.0	
	Rarely	8	16.0	14	28.0	
	Never	2	4.0	1	2.0	
Feel lonely	Always	5	10.0	0	0.00	0.040 Sig
	Often	0	0.0	4	8.00	
	Sometime	8	16.0	9	18.0	
	Rarely	23	46.0	27	54.0	
	Never	10	20.0	14	28.0	
Feel happy	Never	19	38.0	5	10.0	0.006 HS
	Rarely	18	36.0	26	52.0	
	Sometimes	8	16.0	15	30.0	
	Often	1	2.0	3	6.0	
	Always	4	8.0	1	2.0	

* Fisher's exact test was employed for each comparison..

Sig: significant, HS: highly significant, NS: not significant

Table 3 highlights the psychological QoL differences between the thalassemia and control groups. Children with thalassemia were significantly more likely to report always feeling sad (24%) compared to controls (16%), with a highly significant difference ($p = .002$).

In terms of anger and irritability, no significant differences were observed between the two groups ($p = .559$). However, feelings of loneliness were more prevalent in the thalassemia group, with 10% reporting

always feeling lonely compared to 0% in the control group. Conversely, children in the control group were more likely to rarely or never feel lonely, with the difference reaching statistical significance ($p < .05$).

Notably, the frequency of thalassemia patients reporting that they never felt happy (38%) was significantly higher than in the control group (10%, $p = .006$).

Table 4

Levels of Psychological Aspect QoL in Thalassemia and Control Groups

Psychological aspect level	Groups				P. value*
	Thalassemia (n=50)		Control (n=50)		
	No.	%	No.	%	
Good (15-20)	2	4.0	10	20.0	0.030 sig
Fair (8-14)	43	86.0	38	76.0	
Poor (<8)	5	10.0	2	4.0	

*Fisher's exact test used in comparison

sig: significant

Table 4 illustrates that only 4% of thalassemia patients achieved a "good" level of psychological QoL, compared to 20% of controls. Conversely, a higher proportion of thalassemia patients (10%) reported poor psychological QoL compared to controls (4%). These differences were statistically significant ($p = .030$).

This study evaluated the quality of life (QoL) in school-age children with beta-thalassemia major compared to healthy peers, focusing on both physical and psychological domains. The results highlighted significant disparities between the two groups, with thalassemia patients consistently reporting poorer QoL scores. These findings underscore the multifaceted challenges faced by children with beta-thalassemia major and align with the broader body of literature exploring the impacts of this chronic condition.

Discussion and Conclusion

Children with beta-thalassemia major reported significantly higher frequencies of physical weakness and lower energy levels compared to their healthy counterparts. Only 2% of thalassemia patients always felt energetic, compared to 18% of controls. These findings corroborate earlier studies, such as those by Ismail et al. (2006) and Hossain et al. (2023), which found that chronic anemia and frequent transfusions severely impact the physical stamina of affected children (Hossain et al., 2023; Ismail et al., 2006). Additionally, the inability to participate in sports and other physical activities was significantly more pronounced in the thalassemia group, a finding consistent with the work of Hamdy et al. (2021), who noted that physical inactivity is a prevalent issue in children with beta-thalassemia due to disease-related fatigue and medical complications (Hamdy et al., 2021).

The majority of thalassemia patients fell into the "just" or "poor" categories for physical QoL, with only 14% achieving "good" scores compared to 78% in the control group. These results align with studies by Baker et al. (2013) and Al-Salehe et al. (2015), which demonstrated that growth retardation, delayed puberty, and frequent hospitalizations significantly impair physical health outcomes in this population (Al-Salehe et al., 2015; Baker et al., 2013). Chronic iron overload, a common consequence of repeated blood transfusions, further exacerbates physical health issues.

The psychological aspect of QoL also revealed marked differences. Thalassemia patients reported significantly higher frequencies of sadness, loneliness, and a lack of happiness compared to the control group. For example, 24% of thalassemia patients always felt sad compared to 16% of controls, with 38% feeling sad sometimes. These findings are consistent with those of Jabbarifard et al. (2019) and Haghshenas (2019), who identified high rates of emotional distress, including sadness and loneliness, in children with chronic illnesses like beta-thalassemia (Haghshenas, 2019; Jabbarifard et al., 2019).

Interestingly, feelings of anger and irritation did not differ significantly between the groups, indicating that while general emotional distress was higher in thalassemia patients, specific emotions such as anger may not be as prominently impacted. This observation aligns with the findings of Okati et al. (2020), who noted that stress and depression were more prominent than

anger in children with chronic diseases (Okati et al., 2020).

The overall psychological QoL scores indicated that only 4% of thalassemia patients achieved "good" levels compared to 20% of controls, with a higher proportion of thalassemia patients falling into the "poor" category. These results echo the findings of Atia et al. (2021), who reported diminished psychological well-being among children with thalassemia due to the burdens of frequent medical interventions, social stigma, and limited life opportunities (Atia et al., 2021).

The findings of this study align with a growing body of research emphasizing the significant physical and psychological burdens of beta-thalassemia. Pakbaz et al. (2005) and Cheuk et al. (2008) have previously highlighted that children with beta-thalassemia major have significantly lower HRQoL scores than healthy peers, particularly in developing countries where access to advanced treatments is limited (Cheuk et al., 2008; Pakbaz et al., 2005). Moreover, Hossain et al. (2023) demonstrated that even with regular transfusions and chelation therapy, thalassemia patients face ongoing challenges that impede their QoL (Hossain et al., 2023).

The observed disparities in physical and psychological QoL are also consistent with studies that emphasize the role of social and environmental factors. For instance, Mettananda and Higgs (2018) noted that children in socioeconomically disadvantaged regions often experience compounded challenges due to limited healthcare resources, poor disease management, and stigma, all of which further degrade QoL (Mettananda & Higgs, 2018). These factors are particularly relevant in regions like Karbala, where cultural and systemic barriers may exacerbate the challenges faced by thalassemia patients.

This study highlights the pressing need for comprehensive care strategies that address both the medical and psychosocial needs of children with beta-thalassemia major. Interventions such as psychological counseling, physical rehabilitation, and educational support are essential to improve QoL outcomes in this population. The significant differences in both physical and psychological domains underscore the importance of a multidisciplinary approach to care, as advocated by prior studies (Khosravani Shayan et al., 2020; Kiani et al., 2019).

This study has several limitations that should be considered when interpreting the results. First, the study employed a purposive sampling method, which may limit the generalizability of the findings to all children with beta-thalassemia major. Additionally, the study relied on self-reported data, which is subject to recall bias and may not fully capture the participants' experiences. Furthermore, the cross-sectional design precludes the ability to establish causal relationships between beta-thalassemia major and reduced QoL outcomes. Finally, the study did not assess other potential influencing factors, such as socioeconomic status or parental education, which could have provided a more nuanced understanding of the observed differences.

Future studies should consider employing larger, randomly selected samples to improve the generalizability of findings. Longitudinal designs could provide insights into how QoL evolves over time and in response to interventions. Additionally, research should explore the impact of contextual factors, such as socioeconomic conditions, healthcare access, and family support, on QoL outcomes in children with beta-thalassemia major. Investigating the efficacy of specific interventions, such as cognitive-behavioral therapy or acceptance and commitment therapy, in improving QoL outcomes could also yield valuable insights. Finally, comparative studies across different cultural and healthcare settings would enhance understanding of the global burden of beta-thalassemia.

To address the multifaceted challenges faced by children with beta-thalassemia major, healthcare providers should adopt a multidisciplinary approach to care. Regular psychological counseling and support groups can help alleviate emotional distress, while tailored physical rehabilitation programs can improve physical stamina and participation in activities. Schools should implement inclusive practices to support the academic and social integration of children with chronic illnesses. Additionally, public health initiatives should focus on raising awareness about thalassemia to reduce stigma and foster a supportive environment for affected families. Collaborative efforts between healthcare providers, educators, and policymakers are crucial to improving QoL outcomes for this vulnerable population.

Acknowledgments

We would like to express our appreciation and gratitude to all those who cooperated in carrying out this study.

Declaration of Interest

The authors of this article declared no conflict of interest.

Ethical Considerations

The study protocol adhered to the principles outlined in the Helsinki Declaration, which provides guidelines for ethical research involving human participants. Ethics approval was obtained from the University of Babylon Ethics Committee (approval number: 48-2023)."

Transparency of Data

In accordance with the principles of transparency and open research, we declare that all data and materials used in this study are available upon request.

Funding

This research was carried out independently with personal funding and without the financial support of any governmental or private institution or organization.

Authors' Contributions

All authors equally contributed to this study.

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