Original Article
DOI: https://doi.org/10.70749/ijbr.v3i6.2984

INDUS JOURNAL OF BIOSCIENCE RESEARCH
https://ijbr.com.pk
ISSN: 2960-2793/ 2960-2807

# Quality of Life in Transfusion-Dependent Thalassemia Patients Admitted to CMH, Peshawar: Case-Control Study

**Sadaf Ibrahim[1], Faryal Ali[2], Nayyar Ahmed[3]**

[1-3]Paediatric Department, CMH Peshawar, KP, Pakistan.

## ARTICLE INFO

**Keywords:** Transfusion-dependent Thalassemia, Quality of Life, Pediatric Health, PedsQL™, Case-control Study, Pakistan.

**Correspondence to:** Sadaf Ibrahim, Resident Paeds, Paediatric Department, CMH Peshawar, KP, Pakistan.
**Email:** sadaf.ibrahim07@gmail.com

**Declaration**
**Authors' Contribution**
All authors equally contributed to the study and approved the final manuscript

**Conflict of Interest:** No conflict of interest.

**Funding:** No funding received by the authors.

**Article History**
Received: 21-02-2025 Revised: 02-06-2025
Accepted: 12-06-2025 Published: 30-06-2025

## ABSTRACT

**Objective:** To assess the quality of life (QoL) in transfusion-dependent thalassemia (TDT) patients admitted to Combined Military Hospital (CMH), Peshawar, and compare it with healthy controls. **Materials and Methods:** A case-control study was conducted at CMH, Peshawar, using a non-probability consecutive sampling technique. A total of 100 participants were included: 50 diagnosed TDT patients and 50 healthy controls. Inclusion criteria for the TDT group consisted of patients aged 5 years or older, receiving regular blood transfusions, and providing informed consent. Healthy controls were age- and gender-matched individuals with no chronic illnesses. Exclusion criteria included non-transfusion-dependent thalassemia, severe cognitive impairments, and refusal to provide consent. The PedsQL™4.0 Generic Core Scales questionnaire, a validated tool for assessing QoL, was used to collect data. T-tests and chi-square tests were performed to compare QoL scores between groups. **Results:** The study included 50 thalassemia patients (30 males and 20 females) and 50 healthy controls (24 males and 26 females). The mean age of thalassemia patients was 11.20 ± 4.04 years, while the control group had a mean age of 10.96 ± 4.30 years, with no significant difference between the groups ($p = 0.77$). The mean QoL score was significantly lower in thalassemic patients (82.59 ± 5.13) compared to controls (88.22 ± 2.65) ($p < 0.001$). **Conclusion:** Thalassemia significantly reduces QoL in affected individuals compared to healthy peers, irrespective of gender and age. This highlights the need for holistic healthcare approaches, including psychological support, to improve the well-being of TDT patients.

## INTRODUCTION

Thalassemia is a genetic hematological disorder that arises due to mutations in genes and the formation of abnormal hemoglobin.[1] It has two major types: alpha-thalassemia and beta-thalassemia, depending on whether the α- or β-chain of hemoglobin is affected.[2] β-thalassemia, also called thalassemia major, is its most severe form and is prevalent in the Middle East and Southeast Asia. The inheritance pattern of this disease is autosomal recessive; meaning that both parents must have the defective gene for it to manifest in their offspring.[3] Due to decreased or missing hemoglobin chain formation, the destruction of abnormal red blood cells occurs, resulting in chronic anemia.[4] In the first two years of life, manifestations of thalassemia major may include jaundice, growth retardation, skeletal abnormalities (e.g., frontal bossing), an enlarged liver and spleen, and severe fatigue.[5] Without treatment, these conditions can result in serious complications such as cardiac failure, endocrine dysfunction, and decreased life expectancy.[6]

Transfusion-dependent thalassemia (TDT) is a type of thalassemia that requires regular blood transfusions to maintain a sufficient level of healthy hemoglobin, prevent severe anemia, support normal growth, alleviate symptoms, and prevent bone deformities and organ damage. However, regular transfusions are not free of complications and can result in iron overload, leading to hepatic cirrhosis, cardiac issues, and diabetes. To address iron overload, these patients require iron chelation therapy to remove excess iron. Chelation therapy often requires hospital admission. Another reason for hospitalization can be the management of complications such as infections, heart issues, or transfusion-related side effects.[7]

Quality of Life (QoL), as defined by the World Health Organization, is a person's subjective perception of their well-being, including physical, mental health, social connections, and environmental factors; for individuals thalassemia which is chronic disease, maintaining a high QoL can be particularly challenging due to the disease's pervasive impact on their daily lives, psychological state, and social interactions.[8] Numerous studies have evaluated

the quality of life (QoL) in thalassemia patients using standardized instruments such as the WHO-QOL-BREF and the SF-36 Health Survey.[1, 9, 10] Research findings suggest that individuals with transfusion-dependent thalassemia (TDT) report substantially lower QoL scores than healthy individuals, especially in areas related to physical functioning, emotional health, and social involvement. Additionally, factors like frequent hospital stays, pain, the burden of ongoing treatment compliance, and social stigma have been identified as significant contributors to diminished QoL in these patients.[11]

There is an increasing burden of TDT and its significant impact on the lives of patients. Despite advancements in clinical management and improved survival rates, the chronic nature of the disease, along with the requirements of regular transfusions and iron chelation therapy, continues to adversely affect patients' quality of life (QoL). Due to limited resources and varying healthcare quality across different regions, understanding the QoL in TDT patients is important for informing policymakers, allocating healthcare resources, and providing psychosocial support. This study aims to fill the knowledge gap in the local population, as to our knowledge, no studies exist on the Peshawar population

The objective of this study was to determine the QoL in TDT Patients admitted to Combined Millitary Hospital, Peshawar

## MATERIALS AND METHODS

This case-control study was conducted at the Combined Military Hospital (CMH) in Peshawar, Pakistan, on 100 participants (50 admitted thalassemia cases and 50 healthy controls) using a non-probability consecutive sampling technique from January 10, 2024, to September 15, 2024. Ethical approval for this study was obtained from the Institutional Review Board of the hospital. Informed consent was obtained from all participants or their legal guardians prior to their inclusion in the study. A sample size of 22 (11 per group) was calculated at a 95% confidence interval with a power of 80%, using mean Quality of Life (QOL) scores of 82.4 ± 5.54 for the thalassemia group and 87.79 ± 2.91 for the healthy control group, based on a previous study[12]. For normality assumption we have taken total 100(50 per group).

The study included patients diagnosed with transfusion-dependent thalassemia who were aged 5 years and older. Participants were those receiving regular blood transfusions at CMH, Peshawar, and who provided informed consent. Exclusion criteria for the study included patients with non-transfusion dependent thalassemia, individuals with severe cognitive impairments that would preclude their participation, and patients who declined to provide informed consent.

The data were collected with the aid of a validated and standardised questionnaire, the PedsQL™4.0 Generic Core Scales, which measures the health-related quality of life in children and adolescents. It comprises 23 questions with four major sections: Physical Functioning (Scaled at 8 items), Emotional Functioning (Scaled at 5 items), Social Functioning (Scaled at 5 items), and School Functioning (Scaled at 5 items). They evaluated the Physical Functioning domain concerning the extent health interferes with participating in the basic physical activities of walking, running, or any strenuous activity. In the Emotional Functioning domain, the well-being of the respondent in terms of anxiety, and feelings of sadness, anger among others is captured and assessed. The Social Functioning domain examined how respondents relate with and manage their peers while the School Functioning domain assessed the influence of health status on school attendance and general performance. Scoring was done in such a way that graded scores were allocated to each of the problems on a scale of 0-4, where 0 denoted "Never a problem" and 4 "almost always a problem". After that, the ingredients are recoded for each range performance of the respondents, which ranges from 0-100, high scores show high mean quality of life levels.

Data were analyzed using R software (version 4.3.3) with descriptive statistics used to summarize demographic and QoL score. Inferential statistics, including t-tests and chi-square tests, were employed to assess differences in quality of life scores across gender and age groups. the significance level was set at $p < 0.05$.

## RESULTS

**Table 1** presents the demographic characteristics of thalassemic and control participants. The study included 50 thalassemic patients and 50 control participants. There was no significant difference in gender distribution between the groups ($p = 0.23$), with 26 (52.0%) females and 24 (48.0%) males in the control group, and 20 (40.0%) females and 30 (60.0%) males in the thalassemia group. The mean age of the control group was 10.96 ± 4.30 years, while the mean age of the thalassemia group was 11.20 ± 4.04 years, showing no significant difference ($p = 0.77$). Similarly, age distribution did not differ significantly ($p = 0.84$) between the groups: 26 (52.0%) participants in the control group and 27 (54.0%) in the thalassemia group were aged 11-18 years, while 24 (48.0%) in the control group and 23 (46.0%) in the thalassemia group were aged 5-10 years.

Among thalassemic patients, 13 (26%) received more than 15 transfusions in the last year, while 11 (74%) received up to 15 transfusions **(Fig. 1)**.

**Table 2** compares the quality of life (QOL) scores between thalassemic patients and controls. The mean QOL score was significantly lower in the thalassemia group (82.59 ± 5.13) compared to the control group (88.22 ± 2.65), with a p-value of <0.001, indicating a statistically significant difference.

**Table 3** presents a gender-based comparison of quality of life (QOL) scores between thalassemic and control participants. Among females, the mean QOL score was significantly lower in the thalassemia group (81.30 ± 4.95) compared to controls (87.65 ± 2.94), with a p-value of <0.001. Similarly, for males, the thalassemia group had a significantly lower mean QOL score (83.45 ± 5.15) compared to the control group (88.83 ± 2.20), with a p-value of <0.001.

Quality of life between thalassemic and healthy control in both age groups shows that mean score is lower in thalassemic than healthy control. **(Fig 2)**

**Table 1**

*Demographic of the thalassemic and normal participants*

| Characteristic | Control, N = 50 | Thalassemia, N = 50 | p-value* |
|---|---|---|---|
| Gender, n (%); | | | |
| Female | 26 (52.00) | 20 (40.00) | 0.23 |
| Male | 24 (48.00) | 30 (60.00) | |
| Age, Mean ± SD | 10.96 ± 4.30 | 11.20 ± 4.04 | 0.77 |
| Age groups, n (%); | | | |
| 11-18 years | 26 (52.00) | 27 (54.00) | 0.84 |
| 5-10 years | 24 (48.00) | 23 (46.00) | |

*Pearson's Chi-squared test; Welch Two Sample t-test

**Figure 1**

*Pattern of transfusion among thalassemic patients*

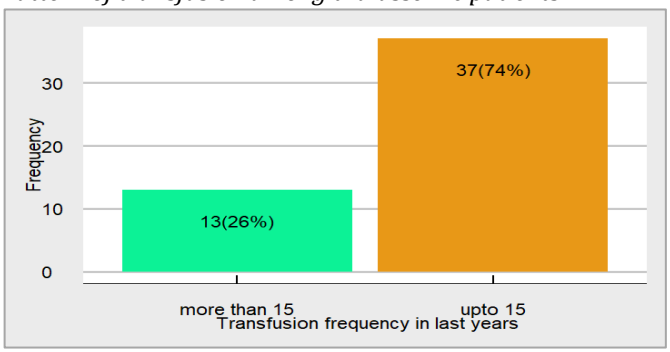


**Table 2**

*Comparison of quality of life score between thalassemia and controls*

| Characteristics | Control, N = 50 | Thalassemia , N = 50 | p-value |
|---|---|---|---|
| **QOL Score** | 88.22 ± 2.65 | 82.59 ± 5.13 | <0.001 |

Welch Two Samples t-test

**Figure 2**

*Quality of life between thalassemic and healthy control in both age groups*

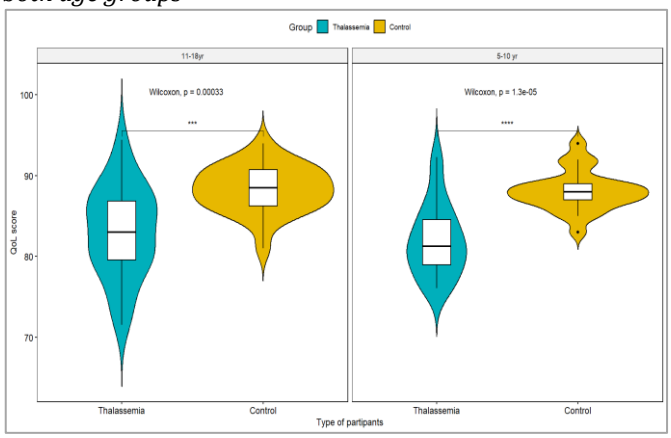


**Table 3**

*Comparison of quality of life score between thalassemia and controls in both genders*

| Characteristic | Female, N = 46 | | | Male, N = 54 | | |
|---|---|---|---|---|---|---|
| | Control, N = 26 | Thalassemia, N = 20 | p-value | Control, N = 24 | Thalassemia, N = 30 | p-value |
| **QOL Score** | 87.65 ± 2.94 | 81.30 ± 4.95 | <0.001 | 88.83 ± 2.20 | 83.45 ± 5.15 | <0.001 |

*Welch Two Sample t-test

## DISCUSSION

`Our findings found that a considerable proportion of thalassemic patients received frequent blood transfusions in the past year. Overall, the quality of life (QOL) scores were lower in thalassemic patients compared to healthy controls, with thalassemic individuals reporting a poorer QOL irrespective of gender or age group.

The reduced quality of life (QoL) observed among thalassemic patients can be attributed to the multifaceted challenges inherent in the chronic management of the disease, which involves not only the frequent need for blood transfusions but also the cumulative burden of secondary complications such as iron overload.[13] This iron accumulation, a consequence of repeated transfusions, necessitates the use of chelation therapy, a lifelong intervention associated with adverse effects and adherence difficulties, further exacerbating the patients' overall physical and psychological burden.[14] Moreover, the regularity of hospital visits disrupts educational, professional, and social engagements, imposing a sense of dependency and diminishing autonomy, which in turn fosters a sense of frustration and anxiety.[15] Compounding these issues are the disease's detrimental effects on growth and development, particularly in pediatric patients, leading to delayed puberty, short stature, and other developmental anomalies that contribute to negative self-perception and impaired social functioning. Collectively, these factors alongside the societal stigma often attached to visible symptoms and the perpetual uncertainty surrounding disease progression culminate in a substantially diminished QoL for thalassemic individuals compared to their healthy counterparts.[16]

The demographic characteristics of the thalassemic and control participants in Table 1 show several key findings that align with similar studies on the topic. The first notable aspect is the lack of significant difference in gender distribution between the groups (p = 0.23), which is consistent with the findings by Shafie et al.[1] in a Malaysian cohort where male and female participants showed similar distribution in thalassemia studies(4). Similarly, in both this study and the one conducted by Maheri et al. [17] in Iran, gender differences did not emerge as significant in the quality of life assessments.

The mean age of the thalassemia group (11.20 ± 4.04 years) and control group (10.96 ± 4.30 years) did not differ significantly either (p = 0.77). This finding mirrors the study by Alzahrani et al.[12] where no significant age-related differences were observed between the thalassemic patients and control groups, emphasizing that thalassemia's impact on quality of life (QOL) is likely more related to clinical factors rather than age alone. Furthermore, similar results regarding age distribution across cohorts have been observed in various regions, including the US and UK.[17]

Regarding blood transfusions, 26% of thalassemic patients had more than 15 transfusions in the last year. Regular transfusions are a hallmark of disease management in thalassemia, as noted by Maheri et al.[17], with patients often requiring consistent transfusion to manage anemia and maintain growth. This finding also

aligns with studies conducted in Malaysia and the Middle East, where the number of transfusions correlates strongly with the patient's physical and psychosocial health.[11, 18]

In the current study, the mean QoL score for thalassemia patients was significantly lower (82.59 ± 5.13) compared to the control group (88.22 ± 2.65), with a p-value <0.001 indicating strong statistical significance. Gender-based analysis showed both males and females in the thalassemia group had significantly lower QoL scores compared to their healthy counterparts. Females had a QoL score of 81.30 ± 4.95 in the thalassemia group compared to 87.65 ± 2.94 in the control group, while males scored 83.45 ± 5.15 in the thalassemia group and 88.83 ± 2.20 in the control group. This finding shows that the physical and psychosocial burdens of living with a chronic condition like thalassemia, which impacts daily functioning and overall well-being.

In the Malaysian study, children with transfusion-dependent thalassemia had a mean QoL score of 80.12 ± 13.87, slightly lower than the current study's results. The study also highlighted how factors like increasing age and the use of dual chelation therapies were associated with lower QoL scores(4). In this study, the Psychosocial Health Summary Score (PCHS) was 79.39 ± 14.81, further supporting the notion that psychological and emotional well-being is a key factor in determining QoL in thalassemia patients. The lower QoL score in this study could be attributed to the inclusion of more severe cases or different healthcare support systems in Malaysia.[11]

Alzahrani's study reported a mean aggregate QoL score of 82.04 ± 15.54 for thalassemia patients, which is quite comparable to the current study's findings. However, the control group in that study had a QoL score of 87.86 ± 12.9, which aligns closely with the control group scores in the current study (88.22 ± 2.65). Both studies indicate that while the QoL scores in thalassemia patients are lower, the difference remains statistically significant across physical and psychological health domains.[12]

Drahos et al.[18] conducted qualitative research in the USA and UK, where thalassemia patients reported significant disruptions to QoL, particularly in domains like daily activities, psychological well-being, and social interactions(3). While this study didn't provide precise QoL scores, it highlighted the major contributors to reduced QoL, such as chronic fatigue, pain, and the need for lifelong treatment regimens like iron chelation therapy. The narrative provided by this study underscores the same challenges identified in quantitative studies like the current one.

## CONCLUSION

Based on our findings, it can be concluded that the quality of life is significantly lower in thalassemic patients compared to healthy individuals, regardless of gender or age group. These results emphasize the need for healthcare providers to implement comprehensive care strategies that address both medical and psychosocial aspects of thalassemia. Tailored interventions, such as psychological support and community programs, can improve the quality of life for thalassemic individuals and enhance patient satisfaction.

## REFERENCES

1. Shafique, F., Ali, S., Almansouri, T., Van Eeden, F., Shafi, N., Khalid, M., Khawaja, S., Andleeb, S., & Hassan, M. U. (2023). Thalassemia, a human blood disorder. *Brazilian Journal of Biology*, *83*. https://doi.org/10.1590/1519-6984.246062
2. Vijian, D., Wan Ab Rahman, W. S., Ponnuraj, K. T., Zulkafli, Z., & Mohd Noor, N. H. (2021). Molecular detection of Alpha thalassemia: A review of prevalent techniques. *Medeniyet Medical Journal*. https://doi.org/10.5222/mmj.2021.14603
3. Ali, S., Mumtaz, S., Shakir, H. A., Khan, M., Tahir, H. M., Mumtaz, S., Mughal, T. A., Hassan, A., Kazmi, S. A., Sadia, Irfan, M., & Khan, M. A. (2021). Current status of beta-thalassemia and its treatment strategies. *Molecular Genetics & Genomic Medicine*, *9*(12). https://doi.org/10.1002/mgg3.1788
4. Yang, J., Li, Q., Feng, Y., & Zeng, Y. (2023). Iron deficiency and iron deficiency anemia: Potential risk factors in bone loss. *International Journal of Molecular Sciences*, *24*(8), 6891. https://doi.org/10.3390/ijms24086891
5. Isaiah, A., Kalle Kwaifa, I., Abdulrahman, Y., & Audu Sunday, O. (2024). Prevalence of thalassemia in Nigeria: Pathophysiology and clinical manifestations. *Clinical Medicine And Health Research Journal*, *4*(2), 806-815. https://doi.org/10.18535/cmhrj.v4i2.325
6. Lisco, G., Giagulli, V. A., Iovino, M., Zupo, R., Guastamacchia, E., De Pergola, G., Iacoviello, M., & Triggiani, V. (2021). Endocrine system dysfunction and chronic heart failure: A clinical perspective. *Endocrine*, *75*(2), 360-376. https://doi.org/10.1007/s12020-021-02912-w
7. Locke, M., Reddy, P. S., & Badawy, S. M. (2022). Adherence to iron chelation therapy among adults with thalassemia: A systematic review. *Hemoglobin*, *46*(4), 201-213. https://doi.org/10.1080/03630269.2022.2072320
8. Cai, T., Verze, P., & Bjerklund Johansen, T. E. (2021). The quality of life definition: Where are we going? *Uro*, *1*(1), 14-22. https://doi.org/10.3390/uro1010003
9. Tarım, H. Ş., & Öz, F. (2022). Thalassemia major and associated psychosocial problems: A narrative review. *Iranian Journal of Public Health*. https://doi.org/10.18502/ijph.v51i1.8287
10. Etemad, K., Mohseni, P., Aghighi, M., Bahadorimonfared, A., Hantooshzadeh, R., Taherpour, N., Piri, N., Sotoodeh Ghorbani, S., Malek, F., Kheiry, F., Khodami, A., Valadbeigi, T., & Hajipour, M. (2021). Quality of life and related factors in β-thalassemia patients. *Hemoglobin*, *45*(4), 245-249. https://doi.org/10.1080/03630269.2021.1965617
11. Shafie, A. A., Chhabra, I. K., Wong, J. H., Mohammed, N. S., Ibrahim, H. M., & Alias, H. (2020). Health-related quality of life among children with transfusion-dependent thalassemia: A cross-sectional study in Malaysia. *Health and Quality of Life Outcomes*, *18*(1). https://doi.org/10.1186/s12955-020-01381-5
12. Alzahrani, R. A., Almutairi, O. M., Alghoraibi, M. S., Alabdulwahed, M. S., Abaalkhail, M. K., Alhawish, M. K., & Alosaimy, M. T. (2017). Quality of life in transfusion-dependent thalassemia patients. *Journal of Taibah University Medical Sciences*, *12*(5), 465-470. https://doi.org/10.1016/j.jtumed.2017.05.006
13. Pinto, V., & Forni, G. (2020). Management of iron overload in beta-thalassemia patients: Clinical practice update based on case series. *International Journal of Molecular Sciences*, *21*(22), 8771. https://doi.org/10.3390/ijms21228771
14. Goulas, V., Kouraklis-Symeonidis, A., Manousou, K., Lazaris, V., Pairas, G., Katsaouni, P., Verigou, E., Labropoulou, V., Pesli, V., Kaiafas, P., Papageorgiou, U., & Symeonidis, A. (2020). A

multicenter cross-sectional study of the quality of life and iron chelation treatment satisfaction of patients with transfusion-dependent β-thalassemia, in routine care settings in western Greece. *Quality of Life Research*, *30*(2), 467-477. https://doi.org/10.1007/s11136-020-02634-y

15. Nazari, S., Malek, F., Marzo, A., & Bidokhti, A. (2022). The survey on the relationship between frustration and social relationships among patients with thalassemia major in Tehran, Iran. *International Journal of Africa Nursing Sciences*, *17*, 100441. https://doi.org/10.1016/j.ijans.2022.100441
16. Meiyanti M. Factors affecting the quality of life of Thallasemia. Int J Pharmac Res. 2020;12(4):31-9. https://doi.org/10.31838/ijpr/2020.12.04.324
17. Maheri, M., Rohban, A., Sadeghi, R., & Joveini, H. (2019). Predictors of quality of life in transfusion-dependent thalassemia patients based on the precede model: A structural equation modeling approach. *Journal of Epidemiology and Global Health*, *10*(2), 157. https://doi.org/10.2991/jegh.k.191001.001
18. Drahos, J., Boateng-Kuffour, A., Calvert, M., Levine, L., Dongha, N., Li, N., Pakbaz, Z., Shah, F., & Martin, A. P. (2024). Health-related quality-of-Life impacts associated with transfusion-dependent β-thalassemia in the USA and UK: A qualitative assessment. *The Patient - Patient-Centered Outcomes Research*, *17*(4), 421-439. https://doi.org/10.1007/s40271-024-00678-7