ORIGINAL ARTICLE

Psychosocial and academic impact of blood transfusion-dependent diseases on children

Retentissement psychosocial et scolaire des maladies dépendantes des transfusions sanguines en milieu pédiatrique

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Abstract

Introduction: Children with transfusion dependant diseases are confronted with multiple physical, psychosocial and cognitive obstacles, which touches significantly on their well-being and quality of life.
Aim: to assess the quality of life of children with transfusion-dependent diseases using the PedsQL 4.0 scale.
Method: This was a descriptive and a cross-sectional study conducted on children with chronic regular transfusion therapy in the paediatric department A of Hedi Chaker Hospital in Sfax, Tunisia between December 2024 and Mai 2025. We collected demographic informations about the children and their families and the clinical characteristics of the disease. The quality of life was assessed using the PedsQL 4.0 Generic score scales for children aged over 5 years old.
Results: Fifteen children requiring chronic transfusion therapy were included. Eleven families belonged to a low socio-economic class. The mean score of the children's quality of life was 58.3%. The quality-of-life dimension with the highest score was the social function with a mean score of 67% while the dimension with the lowest score was the physical function with a mean score of 50.6%.
Conclusion: Transfusion dependant diseases have major negative impact on the daily lives of affected patients. Understanding the challenges faced by these children and their families is important to guide management decisions aimed not only at prolonging life, but also at improving their overall quality of life.

Keywords: transfusion dependent diseases; child; quality of life; Ped sQL

Résumé

Introduction : Les enfants atteints de maladies nécessitant des transfusions régulières sont confrontés à de nombreux obstacles physiques, psychosociaux et cognitifs, ce qui affecte significativement leur bien être et leur qualité de vie.
Objectif : évaluer la qualité de vie des enfants atteints de maladies dépendantes des transfusions sanguines en utilisant l'échelle Peds QL 4.0.
Méthodes : Il s'agissait d'une étude descriptive, transversale, colligeant tous les enfants recevant une transfusion régulière chronique dans le service de pédiatrie A de l'hôpital Hédi Chaker à Sfax, Tunisie, entre Décembre 2024 et Mai 2025. Nous avons recueilli les données démographiques des enfants et de leurs familles, ainsi que les caractéristiques cliniques de la maladie. La qualité de vie a été évaluée à l'aide de l'échelle générique PedsQL 4.0 chez les enfants âgés de plus de 5 ans.
Résultats : Quinze enfants ont été inclus. Onze familles appartenaient à un milieu socio économique défavorisé. Le score moyen de la qualité de vie des enfants était de 58,3 %. La dimension la mieux notée était le fonctionnement social, avec une moyenne de 67 %, tandis que la dimension la moins bien notée était le fonctionnement physique, avec une moyenne de 50,6 %.
Conclusion : Les maladies nécessitant des transfusions chroniques ont un impact négatif majeur sur la vie quotidienne des patients. Comprendre les difficultés auxquelles ces enfants et leurs familles sont confrontés est essentiel pour orienter les décisions médicales, non seulement pour prolonger la vie, mais aussi pour améliorer leur qualité de vie.

Mots clés : maladies dépendantes des transfusions ; enfant ; qualité de vie ; PedsQL

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Introduction

Chronic diseases have a well-established psychosocial and academic impact. In Tunisia, transfusion-dependent diseases represent a real public health problem. These affected children are confronted with multiple physical, psychosocial, and cognitive obstacles, which weigh significantly on their well-being and quality of life. Measuring the health-related quality of life (QoL) in these children is a unique way to determine the perspective of their disease and its impact on their lives. In this context, we conducted this study to assess the psychosocial and academic repercussions of transfusion-dependent diseases on our patients.

The aim of this study was to assess the quality of life of children with transfusion-dependent diseases using the PedsQL 4.0 scale.

Methods

This was a descriptive and cross-sectional study conducted on children aged between 5 years and 15 years with chronic regular transfusion therapy in the Pediatric Department A of Hedi Chaker Hospital in Sfax, Tunisia, between December 2024 and May 2025.

Exclusion criteria were: children suffering from blood disorders that do not require regular chronic transfusions, such as intermediate beta thalassemia, bone marrow aplasia and children suffering from sickle cell anemia who were under a chronic transfusion regimen.

Data were collected from a questionnaire addressed to the children and their parents about demographic information that includes gender, parents' education, parents' occupation, and socio-economic status.

The clinical characteristics of the disease were collected from patients' charts, which included age at diagnosis, frequency of blood transfusion, prescribed treatments, and complications associated with the disease.

The quality of life was assessed using the PedsQL 4.0 Generic score scales for children aged over 5 years old. The Peds QL questionnaire used consisted of 23 questions that were divided into four scales to measure physical, emotional, social, and school function (1).

The Pediatric Quality of Life Inventory (PedsQL) is one of the most widely used tools to measure health-related quality of life in children and adolescents. Multiple studies have proposed cutoff scores for interpreting PedsQL results. A score above 80% was considered reflective of a normative QoL, a score between 60 and 80% revealed a moderate impairment of QoL, and a score below 60% was indicative of a significantly compromised QoL (2).

Results

Fifteen patients requiring chronic and regular transfusion therapy were included in our study: Major beta thalassemia (n=14) and Blackfan-Diamond anemia (n=1). The mean age was 11.2 years (±3.4). The mean age at diagnosis was 5.7 months (±5.1).

Eight patients were male and seven were female. Of the questioned parents, 13 were mothers. All families had health coverage. Eleven families belonged to a low socio-economic class. Seven children were in elementary school, and ten of them had an average school performance. The questionnaire showed mild absenteeism in nine patients. The socio-demographic and academic characteristics of the patients are shown in Tables 1 and 2.

Table 1. Socio-demographic characteristics of the patients

Socio-demographic characteristic	N
Gender	
Male	8
female	7
Age	
6-10 years old	6
11-16 years old	9
Consanguinity	
Yes	11
No	4
Health coverage	
Yes	15
No	0
Father's Education	
Illiterate	0
Elementary	6
High School	9
University	0
Father's Occupation	
Civil servant	6
Self-Employed	3
Day laborer	5
Unemployed	1
Mother's Education	
Illiterate	2
Elementary	4
High School	8
University	1
Mother's Occupation	
Civil servant	1
Unemployed/Housewife	14
Socio-Economic Status	
Low class	11
Middle Class	3
High Class	1

Table 2. Academic characteristics of our patients

Academic characteristic	N
School	
Pre-School	3
Elementary	7
High School	5
School Performance	
Low (< 10/20)	1
Average (10-15/20)	10
High (>15)	4
Grade repetition	
Yes	5
No	10
Absenteeism	
No	0
Minor (1 day or less per week)	9
Moderate (1 week or less per month)	3
Severe (more than one week a month)	3

Of the patients, 14 had major beta thalassemia. The mean pre-transfusion hemoglobin was 8.4 ±0.78 g/dl, and the annual transfusion requirement was 253±171 ml/kg/year. Eight children were on transfusion therapy every 3 weeks. All parents reported strictly adhering to the scheduled transfusion appointments.

Fourteen patients were on chelation therapy; eight of whom were on Deferiprone alone. Adherence to treatment was intermediate for most of the children (n=7). The complications were dominated by skin pigmentation (n=12), hepatic hemochromatosis (n=10), and immunological disturbances (n=7). The clinical characteristics of the patients' population are summarized in Table 3.

Table 3. Clinical characteristics of our patients

Clinical Characteristic	N Mean (±DS)
Pre-transfusion hemoglobin (g/dl)	8.4 (±0.78)
Number of transfusions per year	15.7 (±10.9)
Annual transfusion requirement (ml/kg/year)	253 (±171)
Annual iron intake (mg/an)	4686 (±4311)
Average serum ferritin (ng/ml)	3664 (±1930)
Disease	
Major Beta-Thalassemia (MBT)	14
Balckfan Diamond Anemia	1
Frequency of blood transfusion	
/ Week	1
/ 2 weeks	1
/ 3 weeks	8
/ Month	4
>/ month	1
Average pretransfusion Hemoglobin	
< 7 g/dl	1
7- 8.9 g/dl	11
>9 g/dl	3
Annual transfusion requirement	
< 200 ml/kg/year	7
201-300 ml/kg/year	6
>300 ml/kg/year	2
Serum ferritin levels	
< 1000 ng/ml	1
1001-2500 ng/ml	3
2501 -5000 ng/ml	9
>5000 ng/ml	2
Chelation treatment	
Deferiprone	8
Deferoxamine+ Deferiprone	3
Deferoxamine+ Deferasirox	2
Deferiprone+ Deferasirox	1
No chelation	1
Treatment adherence	
High	5
Intermediate	7
Low	3
Spleen status	
No splenomegaly	2
Splenomegaly	10
Splenectomy	3

Table 5 presents the mean quality of life (QoL) of the patients. In this study, the quality-of-life dimension with the highest score was the social function, with a mean score of 67%, while the dimension with the lowest score was the physical function, with a mean score of 50.6%. Overall, the mean score of the children's quality of life was 58.3%.

Table 4. complications

Undernutrition	1
Short stature	2
Puberty delay	3
Thalassemia facies	4
Skin pigmentation	12
Glucose dysregulation	
Diabetes	0
Impaired fasting glycemia	1
Impaired glucose tolerance	0
Elevated transaminase	4
Hepatic hemochromatosis	10
Mild	1
Moderate	1
Severe	8
Cardiac hemochromatosis	5
Mild	1
Moderate	4
Severe	0
Allo-immunization	1
Auto-immunization	6

Table 5. Quality of life (QoL) score of our patients

QoL dimension	Mean (±DS)
Physical function	50.6 % (±18.3)
Emotional Function	63.6% (±16.4)
Social Function	67% (±19.9)
School Function	52% (±20.2)
Total QoL	58.3% (±15.1)

Discussion

The majority of the families in our study belonged to a low socioeconomic background, a condition that significantly amplifies the burden associated with their child's illness. We also noticed a high prevalence of fathers working as day laborers and a significant number of unemployed mothers.

In fact, socio-economic disadvantage represents a major challenge for health care and is recognized worldwide as an important factor in health among people of all ages (3). A systematic review by Didsbury et al. (4) examining the impact of socio-economic status (SES) on the quality of life of children with chronic diseases found that the SES of parents is an important determinant of QoL of children with chronic disease. In this review, the most frequently used SES indicators were household income and the level of maternal education.

University-level education was rare among the children's parents (3.3%). Many studies focused on the educational status of the parents, and it was documented that parents' literacy is associated with higher QoL scores for the children (5), an observation least expected considering how higher levels of education for both parents can lead to better employment opportunities and higher household income.

Most studies have also found a statistically significant association between higher levels of maternal education

and improved overall QoL for children across all four conditions (6). They suggest that higher maternal education may enhance caregivers' knowledge, enabling more effective coping strategies in managing their children's health.

In our sample, 73.3% of the children were born to a consanguineous marriage. These findings were similar to other studies in the Maghreb region, like Laghmich et al. (7) in Morocco and Mseddi et al. (8) in Southern Tunisia, who found a rate of consanguinity of 50.25% and 44% in patients with hemoglobinopathies, respectively. In Tunisia, this practice remains prevalent due to deeply embedded cultural norms and socioeconomic incentives. Consanguinity contributes considerably to aggravating the burden of hemoglobinopathies in our population. It increases the likelihood of recessive genetic diseases like beta thalassemia and sickle cell disease (9).

The mean pre-transfusion hemoglobin was 8.4 g/dl, and the majority of the children (73.3%) had a hemoglobin level between 7 and 8.9 g/dl. A low hemoglobin level can lead to chronic fatigue, reduced physical endurance, and cognitive difficulties, which may compromise children's ability to fully engage in daily activities, including school (10).

A pre-transfusion hemoglobin level between 9 and 10 g/dL is essential to ensure normal growth and physical activity (11). Consequently, optimizing transfusion therapy is crucial for improving quality of life (QoL) and overall outcomes in these children.

The high frequency of skin pigmentation and facial dysmorphisms among the children included in the study highlights the significant impact of transfusion-dependent diseases on children's morphological development. This can cause further psychological obstacles, such as changes in body image and self-esteem, due to bone deformities and growth retardation, creating feelings of inadequacy (12). Multiple studies emphasize that facial dysmorphisms can affect self-esteem, social interactions, and the overall quality of life (QoL) (13).

Regarding transfusion therapy, it is encouraging to find that all parents reported attending scheduled transfusion appointments. However, ensuring the appropriate volume of blood for optimal pre-transfusion hemoglobin was sometimes difficult due to shortages in red blood cell concentrates (RBCs), particularly due to insufficient quantities or lack of availability in the blood bank.

In our study, 73.3% of children had serum ferritin levels over 2500 ng/ml. In addition, the high prevalence of hepatic hemochromatosis (66.6%) and myocardial hemochromatosis (33.3%) underscores the serious medical complications associated with transfusion-dependent diseases.

The management of transfusion-dependent diseases involves the use of iron chelators to reduce iron overload caused by regular blood transfusions (14).

However, treatment adherence remains a challenge for many patients, as reflected by the fact that over half of children (66.7%) reported a low or intermediate treatment adherence.

Non-adherence may result from a variety of factors, including the complexity of the dosing schedule, perceived or actual side effects, daily life constraints, and even a feeling of frustration or denial.

Moreover, the unavailability of some of the chelation medication within the country (especially Deferoxamine), combined with the fact that most families cannot afford to obtain it from abroad, helps explain why chelation therapy remains suboptimal for many of the children in our study, leading to serious complications related to iron overload, especially hepatic hemochromatosis.

These logistical obstacles can disrupt continuity of care and adversely affect the health and well-being of children who rely on regular transfusions (1). It is therefore essential to establish mechanisms for promptly resolving supply issues and ensuring treatment availability to guarantee uninterrupted care for patients with transfusion-dependent diseases.

Many studies showed that children with transfusion-dependent diseases had much lower mean health-related QoL scores than their healthy counterparts. The mean total score in our study (58.3%) was similar to those reported from other Arabic countries, including Jordan (59.15%)(15), Egypt (42.25%) (16), Iraq (64.63%) (5), and Saudi Arabia (54.5%) (17). It is worth noting that studies from other countries reported higher QoL mean scores, namely Sri Lanka (72.9%) (13), Thailand (70.44%) (18), and Malaysia (68.9%) (19).

Mikael et al found (5) a negative correlation with age, number of transfusions per year, and serum ferritin and a positive one with the age of starting transfusions and age at diagnosis in relation to the child's mean QoL scores.

Another study conducted by Mettananda et al. (13) on 271 patients with transfusion-dependent BTM has found that splenectomy, short stature, undernutrition, longer hospital stays, and lower paternal education and occupation levels were significantly associated with poor health-related QoL.

The physical functioning dimension had the lowest score among the four domains (50.6%). The low physical functioning scores can be explained by multiple factors, including growth retardation, chronic anemia, and hypoxia causing pain and lack of energy during daily activities.

The emotional function score was also low at 63.6%. The literature demonstrates that comorbidity with mental health disorders increases mortality, morbidity, and overall healthcare costs in patients with thalassemia (20,21). Therefore, routine evaluation of mental health problems is recommended to accommodate the early detection and prompt treatment of mental disorders.

Another burden that thalassemic children are feeling different from friends or siblings in many aspects, such as appearance, academic achievement, sporting capabilities, and social activities. This can result in difficulties with social interaction and stigmatization by those around them. However, the social dimension of quality of life received the highest scores, with an average score of 67%. This suggests that despite the challenges associated with the disease, these children have satisfactory social relationships and good support from those around them.

With regard to the school dimension of quality of life, the results are more concerning, with an average score

of 52%. Among our patients, 66.6% had average results, and one-third of the children had to repeat a year.

These findings support the conclusions of Garaibeh et al. (15), who also reported a low average score in the school domain (46.71%). A cross-sectional study conduted by Elbahy et al in 2023 (22) of children with BTM aged between 6 and 16 found significantly lower verbal, processing speed, perceptual reasoning, and working memory scores compared to matched healthy peers. Another study showed that children with transfusion-dependent β-thalassemia exhibit lower IQ scores than healthy children (20).

Also, fatigue and chronic pain, often linked to their health condition or treatment side effects, present significant obstacles to their academic success. These children may struggle to keep up with the pace of lessons or studying hours. Another major challenge lies in managing frequent absences caused by medical appointments, intensive treatments, or recovery periods. In our study, 40% of children reported moderate to severe absenteeism. These repeated absences can lead to learning gaps and make school reintegration more difficult.

This emphasizes the importance of implementing a more attentive and tailored pedagogical approach as well as educational services to cater to their specific academic needs.

Our study has a number of limitations. Primarily, it was conducted on a small number of patients. Also, it is a cross-sectional study that provided a momentary glimpse of the psychosocial and academic impact of these chronic diseases on the quality of life of the children at a specific point in time, without follow-up data. As such, inference of causality between sociodemographic and clinical characteristics and QoL outcomes is limited.

However, this study paves the way for further exploration of interventions aimed at guiding management decisions designed not only to prolong life but also to ensure that such decisions will improve the overall quality of life of these children.

Conclusion

It is evident that transfusion-dependent diseases have a major negative impact on the daily lives of affected patients. It remains a disabling condition and a substantial psychosocial burden. Clinicians, in collaboration with health educators, family members, and educational and social authorities, should adopt a more holistic and multidisciplinary care approach along with psychosocial support tailored to patients' needs to alleviate the suffering of these children.

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