Factors Affecting Health-related Quality of Life Among Thalassemia Patients, 2020, Sana'a-Yemen

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Abstract

Background:

Identifying and understanding the variables that influence health-related quality of life (HRQoL) in patients with thalassemia is critical to creating more appropriate clinical, counseling, and social support programs to develop treatment results for these individuals. The purpose of this investigation is to investigate the variables that are related with HRQOL in thalassemic patients in Yemen.

Methods:

From July to September 2020, a descriptive, cross-sectional investigation was carried out among Thalassemia patients who attended the Yemen Society for Thalassemia. a total of 344 individuals with Thalassemia between the ages of 5 and 18 years old. Data were gathered by utilizing the Pediatric Quality of Life 4.0 as face to face interview with children and their parents. The scale consisted of four domains (Physical, emotional, social, and school functioning) and other related demographic and clinical characteristics of the patients. coefficient tests as appropriate. Two-tailed, p -value <0.05 was regarded statistically considerable.

Results:

The findings of the investigation displayed that the Thalassemia patients were males with a percentage of (54.9%)The total HRQoL mean score was found to be (50.6 ± 16.5) with the highest mean scores in the social (69.3 ± 20.2) and emotional (55.9 ± 20.7) functioning domains. There was correlation between age, education, residency, and total HRQoL scores, which was statistically significant (P -value <0.05). There was correlation between iron overload complications, pre-transfusion Hb level, received iron chelation, and total HRQoL scores (P -value <0.05).

Conclusions:

Appropriate programs focused at providing psychological support to thalassemia patients are needed to improve their HRQoL. The results also supported the significance of keeping a pretransfusion hemoglobin level of at least 9-10.5 g/dL prior to the transfusion procedure.

Introduction

Thalassemia represents an inherited blood disease characterized by the absence or reduced synthesis of one or more of the four globin chains in a hemoglobin molecule, resulting in chronic anemia.

Thalassemia is a condition in which one or more of the four globin chains in a hemoglobin molecule are absent or reduced in synthesis. (1). Thalassemia is a significant public health issue across the globe, although it is particularly prevalent in the Mediterranean area, Southeast Asia, and Southern China (2). An estimated 23,000 instances of β -thalassemia major are identified in newborn babies each year, and there are an estimated 80 million carriers of β -thalassemia throughout the globe(3).

Yemen is an impoverished nation with limited access to health-care services. In Yemen's western coastal and mountainous regions, the frequency of " β -Thalassemia trait is 4.4%, with an estimated incidence of 11.3/10,000 of homozygous β -Thalassemia births in the western coastal and mountainous areas"(4).

The notion of health-related quality of life (HRQoL) is a multifaceted idea that emphasises the effect of illness and its treatment on an individual's overall well-being(5).

It is likely that health related quality of life (HRQoL) will be a significant consideration when regarding treatment options for individual patients and the allocation of health care resources in the case of chronic diseases like Thalassemia, for which a cure is not possible and treatment may be prolonged(6).

In comparison to the general population, patients with Thalassemia consistently report poorer quality of life (QOL) ratings. This has been proven in every developed nation as well as in low- and middle-income countries, with the greatest impact on physical and general health and the least impact on mental health (7).

In a similar vein, research have shown that children's quality of life (QOL) is significantly decreased across all dimensions, including physical, emotional, social, and school functioning. Youngsters from low- and middle-income nations seem to have a worse quality of life than other children (8).

In their investigation on "Factors affecting the quality of life in Thailand children with Thalassemia" identified the following factors `significant which may influence the quality of thalassemic children. They are the age of the child during the onset of disease, age at first transfusion, pre-transfusion hemoglobin level, and the number of blood transfusions during the past three months, the severity of disease, and iron chelation therapy(5).

The findings of the studies revealed a relationship between quality of life and physical functioning in children who suffer from Thalassemia. The physical functioning of Thalassemia children was shown to be linked to their age, gender, and socioeconomic position (9).

When it comes to chronic illnesses such as Thalassemia, where a cure is unlikely and therapy may be extended, HRQoL is likely to be an important result when deciding on treatment choices for individual patients and allocating health-care resources to those individuals. Human Resource Quality of Life (HRQoL) is also acknowledged as a significant health outcome in child health service research (6, 10).

The United Nations report stated that in the year 2020-2021, more than 19.7 million people need health care services in Yemen, while only less than half of health facilities are still functioning. There are also about 1.5 million IDPs currently suffering from existing vulnerabilities including increased morality among pediatric(11).

The discovery of HRQoL will assist physicians in gaining a better understanding of the requirements of their patients beyond the clinical indicators of illness. In addition, this information can assist health

policy decision-makers in demonstrating the need for adjustments or improvements in how health care services are provided to this group of patients in order to enhance their overall results (9).

The creation of more appropriate clinical, psychological, and social support programs for children and adolescents with Thalassemia might have a direct impact on improving treatment results, particularly in terms of HRQoL of these patients. Additionally, "at-risk groups of children and adolescents might be recognized as candidates for proactive care support", which could be provided to them. As there are limited studies focused on HRQoL of Thalassemia among children and adolescent patients (12).

In Yemen, there has been no research on the variables that influence human resource quality of life (HRQoL) in children and adolescents with Thalassemia. The purpose of our investigation was to examine the factors that influence HRQoL in children and adolescents with Thalassemia in Yemen.

Methodology

Participants and settings

The a cross-sectional investigation was done from July to September 2020. was conducted in Yemen Society for Thalassemia -Sana'a-Yemen. Yemen Society for Thalassemia was founded on 15th April 2000, it receives all patients diagnosed with Thalassemia from all hospitals in Sana'a city. It is a non-profit humanitarian society that fights against chronic diseases and cares for infected patients.

Through the time of investigation, all children and adolescents diagnosed with Thalassemia who were registered and followed up at the Yemen Association for Thalassemia were recruited in the study if they met the inclusion criteria.

Inclusion criteria

Children and adolescents in the age range of 5 to 18 years who had been diagnosed with Thalassemia but did not have impaired cognitive function or who did not have a severe clinical condition were eligible for this research if they met the inclusion criteria and agreed to participate.

Exclusion criteria

In children who had impaired cognitive function or who were suffering from a serious clinical condition that may have limited their capacity to participate in the study, or in children whose parents or children refused to give consent or consented to the study.

The sample size was estimated using the EpiCalc software program with Thalassemic population registered was 3273, with a 95% level of the confidence interval and a 5% precision rate, the estimated sample size required was 344 children and adolescents with Thalassemia. using simple random sampling between July to September 2020.

Data Collection and Instrument

In this study, the Pediatric Quality of Life Inventory™ (PedsQL™) 4.0 Generic Core Scale was employed for measuring quality of life in children and adolescents (13). It was necessary to execute an agreement with the MAPI Research Institute in Lyon, France, before the questionnaire could be used in any way.

A software called Statistical Package for the Social Sciences was used to code, input, and analyze the data (SPSS version 25.0.) Between child self-report and parent proxy-report, a 5-point response scale was used (0 = never a problem; 1 = nearly never a problem; 2 = occasionally a problem; 3 = often a problem; 4 = almost usually a problem). Items on the PedsQL™ 4.0 Scales were inverted, scored, and linearly converted from an 0-4 scale to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, and 4=0. This was done to make the scales more easily interpretable. A higher score indicates a greater quality of life.

When used in both physically healthy pediatric populations and pediatric acute and chronic health problems, the original version of the PedsQoL Generic Core Scales has showed strong internal consistency and validity in both situations (14, 15).

Data Analysis

SPSS was used for analyzing the data. Patient characteristics were reported as percentages, means, and standard deviations, with the mean being the most significant. As a measure of HRQOL, both the overall HRQOL score and the summary HRQOL scores were reported as mean and standard deviation. The correlation coefficients Pearson's correlation coefficient, Spearman's rank correlation coefficient, point-biserial correlation coefficient, and the Eta Coefficient test were employed to investigate the connection between HRQOL and each of the demographic, clinical, and therapeutic variables.

Ethical Considerations

Approval was obtained before carrying this study from the Yemen Society for Thalassemia and Genetic Blood Disorders to obtain approval to conduct this study. Parental consent and the child's assent were obtained upon agreeing to participate.

Result

The investigation recruited 344 thalassemia patients. The demographic, clinical characteristic of them are displayed in Table 1. It was detected that almost 54.9% of the participants were male. The age group between 13-18 was 34.9 %, more than a half 60.5% of thalassemia patients lived in urban. only 32.6% of the patients received chelation therapy. however, 61.3% of the patients had Iron overload complications, out of them (28.2%) had a complication of heart disease. most of thalassemia (68.6% pre-transfusion Hb level was less than 7.0 g/dL.

Table 1
Patient characteristics

Demographic& clinical characteristics	N	%
Age group (Year)		
• 5-7	108	31.4
• 8-12	116	33.7
• 13-18	120	34.9
Gender		
• Male	189	54.9
• Female	155	45.1
Residence		
• Urban	208	60.5
• Rural	136	39.5
Types of Thalassemia		
• α -Thalassemia	14	4.1
• β -Thalassemia	205	59.6
• Thalassemia with Sickle cells anemia	125	36.3
Age at diagnosis of Thalassemia (year)		
• < two year	191	55.5
• > two year	153	44.5
Receive chelation therapy		
• Yes	112	32.6
• No	232	67.4
Presence of iron overload complications		
• Yes	211	61.3
• No	133	38.7
Type of iron overload complications(n=211)		
• Heart disease	97	28.2
• Liver disease	61	17.7
• Endocrinopathy	12	3.5

Demographic& clinical characteristics	N	%
• Nephropathy	4	1.2
• Multi-diseases	37	10.8
Pre-transfusion of Hb level		
• <7mg/dl	236	68.6
• 7-8mg/dl	73	21.2
• 8-9mg/dl	26	7.6
• > 9 mg/dl	9	2.6

The total HRQoL mean score was found to be (50.6±16.5) and psychosocial health summary score (59.0±17.3) with the highest mean scores in the social (69.3±20.2) and emotional (55.9±20.7) functioning domains followed by school functioning (52.2±19.3) and lastly lowest mean scores in physical functioning domain (45.1±18.2) Table2

Table 2
summary mean scores of HRQoL domains among
thalassemic patients n=344

Domains	Mean	±	SD
• Physical functioning	45.1	±	18.2
• Psychosocial health summary score	59.0	±	17.3
o Emotional functioning	55.9	±	20.7
o Social functioning	69.3	±	20.2
o School functioning	52.2	±	19.3
Total summary mean scores	50.6	±	16.5

Table (3) indicatw that there was correlation between age group and whole HRQoL summary scores, which was statistically significant (P -value=0.00) with increase age is correlated with increased level of HRQoL summary scores. Also there was correlation between residency and total HRQoL summary scores, which was statistically significant (P -value=0.000) increase number of urban residence is associated with increased HRQoL summary scores. The patients who live in urban area had higher total HRQoL scores, in comparison with patients who live in rural area. However, the study displayed there was no considerable correlation between the total HRQoL summary scoresand gander Table 3.

Table 3
Health Related Quality of life scores of child self-report classified by demographic characteristics
n=344

Demographic Items	Total Physical	TotalEmotional	Total Social	Total School	Total HRQoL
	Mean±SD	Mean± SD	Mean± SD)	Mean± SD	Mean± SD
Age group					
5-7 years	44.7±17.7	56.6±20.0	70.1±19.8	50.0±23.9	45.9±14.5
8-12 years	45.2±19.8	57.5±21.0	69.5±20.4	55.1±19.1	53.4±18.1
13-18 years	45.4±17.2	53.8±21.2	68.5±20.3	50.2±17.9	53.6±15.8
P. value	0.63	0.33	0.76	0.31	0.00
Sex					
Male	45.7±18.9	56.5±21.7	69.7±20.8	51.3±19.7	50.9±17.5
Female	44.4±17.4	55.1±19.6	68.8±19.3	53.3±18.7	50.4±15.2
p. value	0.49	0.51	0.65	0.44	0.75
Residence					
Urban	48.0±18.9	58.6±21.3	72.4±20.8	57.4±18.3	54.1±17.4
Rural	40.6±16.2	51.7±19.4	64.7±18.2	43.3±17.6	45.5±13.7
P. value	0.00	0.02	0.01	0.00	0.000

There was no considerable correlation between the whole HRQoL summary scores and age at diagnosis of Thalassemia and serum ferritin level/ (P -value > 0.05).

There was correlation between types of Thalassemia, iron overload complications and total HRQoL summary scores, which was statistically significant (P -value > 0.000). Patients without iron overload complications had higher whole HRQoL summary mean scores in comparison to patients with iron overload complications.

There was a correlation between age at received iron chelation, pre-transfusion Hb level and total HRQoL summary scores, which was statistically significant (P -value > 0.005). Patients with hemoglobin levels more than 9 g/dL had substantially higher overall HRQoL summary mean scores than those with hemoglobin levels less than 9 g/dL (Table 4).

Table 4
Health Related Quality of life scores classified by Clinical characteristics N=344

Clinical factors	n	Total Physical	Total Emotional	Total Social	Total School	Total HRQoL
		Mean(SD	Mean ±SD	Mean±SD	Mean ±SD	Mean± SD
Types of Thalassemia						
• αThalassemia	14	53.3±19.4	63.2±24.6	75.7±27.2	57.5±25.0	59.5±19.3
• β-Thalassemia	205	45.4±18.1	57.2±20.1	69.7±20.1	52.5±19.2	51.4±16.5
• Thalassemia .S.C.A	125	43.6±18.2	53.0±21.2	68.0±19.4	50.8±18.5	48.5±15.9
p. value		0.04	0.08	0.36	0.51	0.03
Age at diagnosis Thalassemia						
• < two year	191	44.6±16.5	55.7±20.3	69.2±19.1	53.4±19.0	50.5±15.6
• > two year	153	45.7±20.2	56.2±21.5	69.5±21.5	50.7±19.6	50.9±17.6
p. value		0.57	0.84	0.91	0.28	0.79
Iron over load complications						
• Yes	211	40.0±16.4	51.4±19.5	65.3±20.5	48.4±18.5	46.7±15.0
• No	133	53.2±18.1	63.2±20.8	75.6±17.8	59.0±18.8	56.8±17.0
p. value		0.00	0.00	0.00	0.00	0.00
Pre-transfusion of Hb level						
• <7 mg/dl	236	41.8±17.1	53.2±20.6	66.6±20.1	51.1±19.9	46.4±15.7
• 7-9 mg/dl	98	50.9±17.5	60.5±19.1	74.4±17.8	53.8±18.1	54.6±14.9
• ≥ 9 mg/dl	10	65.0±27.2	73.5±24.0	81.5±28.0	57.8±15.7	62.6±20.7
p. value		0.00	0.00	0.00	0.44	0.00
Serum ferritin level(n=232)						
• ≤2500 ng/ mL	28	48.9±17.8	56.7±18.9	69.8±20.2	54.5±17.0	50.3±14.7
• > 2500 ng/ mL	204	43.3±17.3	54.2±20.3	68.4±19.9	52.0±18.8	49.0±16.3
p. value		0.10	0.53	0.77	0.59	0.37

Clinical factors	n	Total Physical	Total Emotional	Total Social	Total School	Total HRQoL
		Mean(SD	Mean ±SD	Mean±SD	Mean ±SD	Mean±SD
Age at received Iron chelation						
• ≤8 Years	77	41.8±16.	54.3±18.3	67.4±20.1	56.3±17.3	49.8±17.5
• >8 Years	35	49.8±17.	57.8±23.5	71.5±18.2	54.6±19.6	50.7±16.5
p. value		0.01	0.39	0.30	0.67	0.03

There was correlation between regimen of blood transfusion,regimen of received iron chelation,frequency of ferritin measured,access to the treatment society thalassemia and total HRQoL summary scores, which was statistically significant(P -value<0.05).

Patients who regularly received iron chelation had higher HRQoL mean summary scores than those who did not received iron chelation and who received it occasionally.Patients who easy access to the treatment society had higher HRQoL mean summary scores than other accessible Table 5.

Table 5

Quality of life ratings from children's self-reports were categorized according to the patients' treatment and health-care features.n=344

Treatment and Health Service Characteristics	N	Total Physical	Total Emotional	Total Social	Total School	Total HRQoL
		Mean(SD	Mean ±SD	Mean±SD	Mean ±SD	Mean± SD
Regimen of blood transfusion						
Regularly transfused	177	44.5±17.8	57.1±20.4	69.8±19.9	53.0±17.3	50.8±16.6
Occasionallytransfused	152	43.8±17.4	53.1±20.3	67.5±20.4	50.9±21.3	49.1±15.9
Not transfused	15	65.0±20.9	71.0±23.6	81.6±15.8	55.0±21.4	64.5±16.2
p.value		0.000	0.003	0.032	0.786	0.002
Regimen of receive iron chelation						
Regularly received	44	49.1±16.5	59.3±20.5	73.6±17.2	60.9±16.5	55.9±16.5
Occasionally received	68	41.2±16.3	53.2±19.8	65.9±21.2	52.6±18.5	49.6±16.2
Not received	232	45.4±18.8	56.1±21.1	69.6±20.2	50.1±19.7	50.7±16.6
p.value		0.021	0.022	0.048	0.047	0.047
Frequency of ferritin measured						
Every month	5	39.4±10.7	50.0±23.5	66.0±19.5	46.3±18.8	46.9±13.7
Every two month	6	46.4±16.2	55.0±14.8	70.8±13.5	55.0±19.4	53.4±13.6
Every three month	42	46.1±20.2	53.1±21.2	67.5±20.6	57.7±17.7	50.9±18.4
Every six month	113	45.5±15.8	58.3±21.0	71.6±17.9	51.9±19.3	52.4±15.5
Every twelve month	66	40.2±18.4	49.5±17.1	64.7±22.7	50.1±19.4	46.7±16.9
Never	112	47.4±19.6	58.7±21.9	70.4±20.6	51.8±20.5	51.2±16.7
p.value		0.031	0.049	0.049	0.048	0.049
Adequate of blood supplies n=329						
Yes	249	45.3±16.8	55.5±19.5	67.6±18.9	53.1±18.1	50.5±16.0
No	80	40.6±19.5	54.5±23.2	72.3±23.3	48.6±22.4	48.5±17.2
p. value		0.034	0.709	0.072	0.143	

Treatment and Health Service Characteristics	N	Total Physical	Total Emotional	Total Social	Total School	Total HRQoL
		Mean(SD	Mean ±SD	Mean±SD	Mean ±SD	Mean± SD
Delayed in blood transfusion(n=329)						0.358
No delays	36	50.0±19.9	55.5±20.4	72.9±16.6	56.4±15.1	54.9±15.7
Occasional delays	179	43.1±15.8	54.5±19.5	66.1±20.4	52.0±17.4	48.8±15.5
Frequent delays	114	44.5 ±18.8	56.4 ±21.9	71.7±20.3	50.6±23.1	50.5±17.4
p.value		0.877	0.560	0.306	0.146	0.505
School absenteeism						
None	31	53.7±15.5	63.7±16.5	81.7±14.3	62.6±16.3	61.7±12.7
1-5 days	269	45.0±18.1	55.2±20.2	68.4±19.6	51.3±18.5	50.1±16.3
Over 6 days	44	39.6±19.5	54.4±25.2	66.0±24.5	47.0±23.5	46.4±18.1
p.value		0.001	0.0055	0.005	0.003	0.000
Access to the treatment society						
Very easy	32	45.8±18.6	57.3±22.2	70.3±22.7	57.0±21.7	54.1±17.0
Easy	109	50.1±18.4	59.4±22.4	73.8±18.4	59.9±19.1	55.2±16.8
Difficult	142	45.5±17.8	56.1±19.6	70.0±19.9	48.4±17.9	50.4±15.8
Very Difficult	32	30.6±11.9	44.2±16.5	54.8±16.7	40.0±10.9	37.4±10.9
Available but tooexpensive	29	39.4±13.2	50.6±15.8	62.1±19.1	45.7±17.1	44.7±16.5
p.value		0.000	0.002	0.00	0.000	0.000

Discussion

Thalassemia refers to a serious medical condition that has a negative effect on the patient's quality of life (16). In patients with Thalassemia, measuring their health-related quality of life (HRQoL) is a unique approach to assess the patients' viewpoint of their condition and its influence on their lives (17).

When it comes to the availability of primary care services, there is a difference between rural and urban settings. As a result, the current study found that the majority of participants lived in urban areas due to

the availability of primary care services, which is consistent with the findings of another Iranian study that found that the majority of Thalassemia patients came from urban areas (18). Furthermore, the place of residence was accompanied with HRQoL in all domains and total HRQoL summary scores in this study. When compared to children from rural areas, children from urban areas showed greater HRQoL. One possible explanation is that the youngsters were under continual stress as a result of their long journeys and the transfusion treatments that they underwent throughout their hospitalization.

Iron overload complications were related to HRQoL in this investigation. These findings were not consistent with the study conducted in Thailand (5).

This present investigation found that the majority of patients experienced an Iron-overload problem, with the most likely causes being numerous transfusions, a decreased pre-transfusion hemoglobin level, insufficient chelation treatment, and severe anemia, as revealed by the findings. While other studies have reflected a significantly lower incidence rate of cardiomyopathy among their Thalassemia patients in Dubai (1.8 percent), this study found a significantly lower incidence rate of cardiomyopathy in their patients with a percentage of (1.8%) among their Thalassemia patients (12).

The comparatively high iron overload complication rate in Yemen might be illustrated by the fact that Thalassemia therapy is complicated, expensive, and difficult to obtain due to poverty, thus patients are unable to obtain iron chelating medicines, which assist to reduce the incidence of problems.

The findings of the current investigation showed that more than a half of the patients did not get chelation. This might be explained by a variety of factors, including the lack of chelator in some Yemeni facilities and poor compliance among some of the patients under investigation. Because of the exorbitant expense of transfusions and chelating medicines, the situation is dire.

Another research showed that (67%) of the Thalassemia patients they investigated were undergoing some type of chelation treatment. The present study's findings are in conflict with that other study's findings (19).

According to the findings of this study, patients with a pre-transfusion hemoglobin level more than >9 g/dL had substantially higher overall HRQoL ratings than patients with a pre-transfusion hemoglobin level less than <9 g/dL. Because low hemoglobin levels are accompanied with a variety of symptoms such as fatigue, general weakness, and lower mental alertness in addition to other symptoms, this might explain why patients' HRQoL has been found to be compromised (20). Pre-transfusion Hb level should be supervised routinely to retain an optimal level of 9 to 10.5 g/dL (3, 5, 20).

The results of this study also revealed that the regimen of iron chelation therapy was substantially associated with decreased HRQoL. Thalassemia patients who regularly received the iron chelation treatment and patients who occasionally received iron chelation having lower total HRQoL scores when compared with patients not received iron chelation treatment. A repeated course of chelation therapy may result in an increase in iron losses, which may have an indirect effect on the patient's quality of life.

Furthermore, patients who did not delay blood transfusion had better total HRQoL scores when compared with patients delay of blood transfusion but there was no considerable association between total HRQoL scores and delay of blood transfusion.

The findings of this study revealed that the lowest domain score in the current investigation was in physical functioning (45.1 ± 18.2), which was not the same as in the previous studies (73.2 ± 14.9) conducted by Mahmoud (12), who explained the high physical functioning score by stating that these patients had low expectations of physical performance because they had been told that they would not be able to perform.

The Jordan study's low HRQoL ratings in the physical domain revealed that their Thalassemia youngsters felt discomfort, pains, and low energy when doing daily activities (16). The discrepancy in HRQoL domain scores can be explained by the fact that the majority of participants in Malaysian research were homozygous beta-Thalassemia and transfusion dependent, whereas the majority of participants in Thailand studies were not and were not transfusion dependent. Furthermore, it was found that there were variations in cultures, experiences, and attitudes across Thailand, Malaysia, and Yemen, which might be explained by a variety of factors. Another investigation found that the mean score of HRQoL among teenagers was more than 70, indicating that they had strong HRQoL, as evidenced by the fact that they considered themselves as physically active and capable of doing their typical daily routine activities. (15). In the majority of the investigations, the subscales of the psychosocial health summary score were used for assessment (3, 5, 16, 21).

Following the findings of the current research, it was discovered that the domain of school functioning had the lowest mean score. In order to maintain their health, children with Thalassemia must get blood transfusions once every three to four weeks at the Thalassemia Day Care Society. Thalassemia patients may experience extra difficulties such as frequent school absences for Thalassemia visits, difficulty coping with schoolwork, and a lack of energy when doing academic tasks. These difficulties can negatively impact the quality of life. However, this conclusion was in contrast to the findings of an Egypt research, which indicated that school functioning ratings improved as a result of the presence of patients who needed to have their blood transfused at the hospital (22).

The current study showed that age and gender had no significant association with physical function. However, this finding is inconsistent with an investigation reported by Sharma et al (2017). They reflected that age of Thalassemia children and gender were associated with physical functioning while it is identical to the investigations conducted by Sazlina et al (2015), Ismail et al (2006) and Thavorncharoen et al (2010) who reported no significant association between gender and physical function. Also, it is similar to some studies done by Ismail et al (2013), Surapolchai et al (2010) and Torcharus et al (2011). They detect no considerable association between age and physical function.

In a study of all factors that influence the physical summary score, it was discovered that the mean yearly serum ferritin level had a non-significant impact on physical health summary score, with greater serum ferritin levels associated with worse physical quality of life scores. This finding is inconsistent with the

study done by Wasfy et al (2011). This study showed that the type of payment for treatment had not association with physical functioning. According to the findings of one study, patients who were insured by the Universal Health Coverage Scheme had considerably better physical functioning (23).

As regards to clinical factors, the current study showed that emotional functioning was significantly associated with iron overload complications, pre-transfusion Hb level and age at received iron chelation (P-value <0.05) while no significantly associated with types of Thalassemia, age at diagnosis of Thalassemia, family history of Thalassemia, siblings with Thalassemia and serum ferritin level (P-value >0.05).

This finding is inconsistent with the results found by Montarat et al (2010) who reported that iron overload complications, pre-transfusion Hb level and age at received iron chelation, types of Thalassemia. Also, age at diagnosis of Thalassemia, family history of Thalassemia and serum ferritin level were not significant associated with emotional functioning which were consistent with the current study. Also Asrul et al (2020) reported that iron overload complications not significantly associated with emotional functioning. The current studies showed that there was no demographic factors that affect social functioning among Thalassemia patients (P-value >0.05) except place of residency (P-value <0.05). This result was inconsistent with results found by Sazlina et al (2015). There was a statistically considerable relationship between social functioning and both age and educational level. Similarly to the previous study, Thavorncharoensap et al (2010) discovered that age is a major determinant in the development of worse social functioning.

As regards to clinical factors, the current study showed that social functioning was significantly associated with iron overload complications and pre-transfusion Hb level (P-value <0.05) while no significantly associated with types of Thalassemia, age at diagnosis of Thalassemia, family history of Thalassemia and siblings with Thalassemia and serum ferritin level and age at received iron chelation (P-value >0.05). The current study was consistent with the study done by Thavorncharoensap et al (2010) that found pre-transfusion of Hb level was significantly impaired HRQoL in social functioning subscale. They also discovered that patients with anemia who were less than two years old at the time of start and who underwent iron chelation therapy had substantially worse HRQoL in the social functioning subscale. This is in conflict with the findings of the current study.

The current studies showed that there were no demographic factors that affect school functioning among Thalassemia patients (P-value >0.05) except place of residency (P-value <0.05). Basing on an investigation among Malaysian children, school functioning was only associated with age (5).

As regards to clinical factors, the current study showed that school functioning was not significantly associated with any one of clinical factors (P-value >0.05) except for iron overload complications (P-value <0.05). According to the findings of a research conducted among Malaysian children, school functioning was solely related with pre-transfusion hemoglobin levels, and the age at which anaemia first manifested itself was less than two years (5). Aside from that, illness complications were shown to be related with a poor quality of life (16).

It is not feasible to determine if converts in self-rated functioning and well-being would have happened in persons who were not exposed to the same situation because of the study's limitations because there was no control group.

Conclusion

Thalassemia disease restricts the physical and school functioning of the patients. The total HRQoL mean score was found to be the highest mean scores in the social and emotional functioning domains followed by school functioning and lastly lowest mean scores in physical functioning domain.

Recommendations: Human Resource Quality of Life (HRQoL) of Thalassemia patients should be addressed by offering intervention programs that target the impacted domains. Additional aid for patients and their families, particularly psychological support, should be provided as part of these programs in order to prevent mental disorders from developing. Improved patient-centered, flexible, and comprehensive health care services for children with Thalassemia should be implemented in order to reduce the amount of time spent at the Society for Thalassemia while simultaneously improving treatment outcomes.

Abbreviations

HRQoL: Health-Related Quality of Life.; QoL: Quality of Life.; PedsQL: Pediatric Quality of Life Inventory.; WHO: World Health Organization.; IBM SPSS: Statistical Package for Social Sciences.

Declarations

Ethics approval and consent to participate

Approval was obtained prior to carrying this study from the ethical committee of the college of medical sciences of Al-Razi University. All procedures were in accordance with the ethical standards of the institutional and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The purpose and benefits of the study was explained to participants. A parental consent and the child's assent were obtained upon agreeing to participate by answering a "Yes or No" question in the written informed consent form.

Consent for publication

Not applicable.

Availability of supporting data

Data are available from the corresponding author on a reasonable request.

Competing interests

The authors declare that no competing interests.

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Author Contributions

Conceptualization, AG. and NR.; Methodology, AG, NA and MSA.; Investigation and Data Collection, AG and MSA.; Data Analysis, AG and NA.; Writing—original draft, AG and MSA.; Writing—Review for important intellectual content and editing, G, NA and MSA. All authors have read and agreed to the published version of the manuscript.

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