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Review Article

Evaluation of Quality of Life Associated with Pediatrics Transfusion-dependent Thalassemia- A Cross Sectional study

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Abstract

Objectives: Thalassemia is a common blood disorder that may impact the patients quality of life wherefore, we conducted this study to evaluate the quality of life of pediatrics lived with transfusion dependent thalassemia in north Sinai-Egypt.

Design: A cross sectional study, questionnaire-survey form (PedsQL™ 4.0 GCS) was conducted by the children parents.

Setting: The study was conducted in the blood transfusion department at al-Arish general hospital. Which is responsible for all transfusion dependent thalassemia patients in North Sinai.

Patients: parents of 32 children were questioned. children were selected using simple random sampling technique from September 2022 to June 2023. 18 females (56.3%) and 14 males (43.7%).

Results: Children's HRQOL was measured by 23 items in this concise and multidimensional scale. The present study mean total score (46.9 ± 13.5) was lower than that of a study conducted in Egypt 2014 (63.74 ± 13.2) which indicate a lower quality of life The mean physical, Psychosocial health, Emotional, social, and school functioning scale are 42.4±17.5, 49.3± 12.8, 49.3±12.8, 54.7± 12.7, 59.4± 18.5, 33.9±13.4. The largest total scale in the group who have children 8–12 years 50.6± 6.4

Most scales exceeded the minimum reliability standard of 0.70. Internal consistency reliability for the Total Scale Score (α = 0.92), Physical Health Summary Score (α = 90), Psychosocial Health Summary Score (α = 0.87), Emotional functioning score (α = 0.55), Social functioning (α = 90) and School functioning (α = 0.67).

Statistically significant correlation between social functioning and all other subscales, with a Pearson moment correlation coefficient of $r \geq 0.50$ and a p-value ≤ 0.05. Additionally, a strong and statistically significant correlation was found between school functioning and physical functioning with a Pearson moment correlation coefficient of r =0.60 and p <.001, while a moderate and statistically significant correlation was observed between the emotional functioning scale and physical functioning as well as school functioning, with a Pearson moment correlation coefficient of r = 0.4 and a p-value of less than 0.05.

Conclusions

The study findings reveals the negative impact of thalassemia on the physical, Psychosocial health, Emotional, social and school functioning which in return affect negatively on their quality of life. School functioning was the most affected domain this call for a steps and efforts in order to improve. A planned teaching program updated education sessions should be conducted aiming to direct the patients, family and school how to cope with thalassemia, how to connect in order to improve the quality of life of thalassemia children patients, in addition facilitate their life.

thalassemia is chronic disease that have no cure ; management were improved recently but ;preliminary study found that thalassemia have negative impact on the quality of life especially in developing countries. Consequences like Physical deformities; growth retardation; and delayed puberty are all possible. so we aimed to assess the quality of life; especially it is poorly understood in Egypt and there has been minimal research about the influence of thalassemia and its complications on the quality of life. When the impact of quality of life assessed it help in developing policy to deal with.

Keywords: loneliness; isolation; alone; social isolation; depression; mental health; rest ; intervention

Introduction

Thalassemia is the world's most common genetic illness that is passed down the generations.(1) It is an inherited blood disorder in which the body produces abnormal and inadequate globin chain hemoglobin.it is divided into alpha- (α-) thalassemia and beta- (β-) thalassemia.(2) 90 years ago, severe thalassemia was first described by cooly and lee. According to the spectrum of severity, thalassemia was classified as thalassemia major (TM), thalassemia intermedia (TI), and thalassemia minor.(3,4) It was classified as transfusion-dependent and non-transfusion dependent Regarding the need for regular blood transfusion.(5) Geographically, thalassemia is a major public health issue across the Mediterranean, the Middle East, and the Indian subcontinent, as well as Southeast Asia.(6,7) Around 300 million people globally are carriers, with 55 million living in Southeast Asia.(8) Worldwide, around 270 million carriers of hemoglobin disorder and thalassemia, about 30% of them are beta carriers. Annually, between 300,000 and 400,000 babies are born with dangerous hemoglobin disorders 90% of them are in low-middle income countries.(9–13) In Egypt beta thalassemia major is the most common hemoglobinopathy disease.(14,15)

Physical deformities, growth retardation, and delayed puberty are all possible consequences of thalassemia. Thalassemia affects physical appearances, such as bone abnormalities and short height, which contribute to low self-esteem. (16–18) Thalassemia major affects patients' appearance by producing physical abnormalities and delayed puberty, as well as affecting their self-esteem. people with thalassemia major are prone to bone discomfort and gastrointestinal pain, respectively, while hemosiderosis in the endocrine glands causes short stature. (19,20) Heart failure, cardiac arrhythmia, liver disease, endocrine difficulties, and infections are associated with thalassemia complications. (21–23) resulting in a lower quality of life. (24–26)

A patient with thalassemia major can be summarized as "a patient who has no chance of getting a job, getting married, or having children". (27) According to WHO (1996), Quality of Life is defined as an individual's perceptions of their position, specifically in terms of culture and systems of values in which the person's life and in relation to their goals, expectations, standards, and concerns.(28) Previously stated, thalassemia may have a negative influence on the quality of life.(27,29,30).

Because children are less able to express their concerns and are more vulnerable than adults, assessing QOL in children is critical for providing appropriate care, as it aids in detecting the disease's and treatment's effects on children.(31,32) Furthermore, according to a recent study, children's QOL can be utilized as a predictor of health-care expenses and can also be used to identify at-risk groups of children who should receive proactive care coordination.(33,34) A better knowledge of the elements that influence QOL in children and adolescents with thalassemia should lead to the development of more appropriate clinical, psychological, and social support programs to improve treatment results, particularly in terms of QOL

The effects of thalassemia major and its consequences on quality of life are poorly understood in Egypt and There has been minimal research into the influence of thalassemia and its complications on the quality of life(35) Thus, in our study, we aim to study the quality-of-life of patients with transfusion-dependent thalassemia in pediatrics using PedQl questionnaire. This is an important issue as it not only impacts the individual themselves but also the community and society.

Study aims and objectives.

We conducted this study aiming to determine and measure the quality of life of patients with thalassemia who live with chronic blood transfusion physically, socially, and psychologically.

Methodology

Study design, Populations, setting, and sampling technique.

An observational cross-sectional study was conducted by questioning the parents of the participated 32 children who routinely receive their blood transfusion in AGH and included in the study. The study done in the blood transfusion department at al-Arish general hospital. The selection of the study participants done through simple random sampling technique from September 2022 to June 2023. No patient was refused the questionnaire.

Inclusion criteria: Transfusion dependent thalassemia patients of pediatrics 3-18 years old. patient with other comorbidities and complications.

Exclusion criteria: Patients who refused to perform the study questionnaire and refused to participate.

Study tool:

A structured questionnaire-survey form (PedsQL™ 4.0 GCS) in English that translated into Arabic to be easily understood. The PedsQL 4.0 Generic Core Scales consisted of 4 scales: (i) Physical Functioning (eight items); (ii) Emotional Functioning (five items); (iii) Social Functioning (five items); and (iv) School Functioning (five items) , A 5-point Likert scale is utilized across the parent proxy-report (0 = never a problem; 1 = almost never a problem; 2 = sometimes a problem; 3 = often a problem; 4 = almost always a problem). The items are reverse-scored and transformed into a 0–100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0). Therefore, higher scores on the PedsQL 4.0 indicate better HRQOL. The scores for each scale are calculated by adding up the item scores and dividing them by the number of items answered, so that higher PedsQL 4.0 total scores reflect better HRQOL.

Data collection

A trained study research instigator meat with the children's parents to start the interview. Enough time were given to all parent to answer the questionnaire. Each parent answers the questionnaire separately in their specific questionnaire paper. All questionnaires were computerized to be ready for data analysis.

Data analysis

All the data were analyzed using R software. The categorical variables were presented by frequency and percentage. While the continuous variable described by mean with standard deviation.The Physical Health Summary Score (eight items) is the same as the Physical Functioning Subscale. To compute the Psychosocial Health Summary Score, consisting of 15 items, the mean is calculated by adding up the item responses and dividing by the number of items answered in the Emotional, Social, and School Functioning Subscales.We calculated Cronbach's alpha coefficient to determine the scale's internal consistency and reliability. Satisfactory reliability was defined as 0.70 or greater. To assess the feasibility of administering PedsQL 4.Generic Core Scales, and the percentage of missing values was calculated.We assessed the intercorrelation between the scales using Pearson's product-moment correlation coefficient, The correlation is classified as small (0.10-0.29), medium (0.30-0.49), and large (0.50), $p < 0.05$ was considered significant correlation:.

Results:

A total of 32 parents of the participated children were surveyed. Gender distribution among children were 18 females (56.3%) and 14 males (43.7%). They were 3 to 18 years old. The PedsQL™ 4.0 demonstrated a 100% response rate, without any missing responses. This supports the questionnaire's feasibility, and indicates that parents are capable and willing to provide high-quality data on their child's HRQOL and

Question	N (%)
PHYSICAL FUNCTIONING (problems with…)	
1-Walking 100 meters	
Almost never	2 (6.2%)
Sometimes	22 (68.8%)
Often	4 (12.5%)
almost always	4 (12.5%)
2-Running	
Almost never	0(0%)
Sometimes	20 (62.5%)
Often	8 (25%)
almost always	4 (12.5%)
3-**Participating in sports activities or exercise**	
Almost never	2 (6.2%)
Sometimes	16 (50%)
Often	6 (18.8%)
almost always	8 (25%)
4-Lifting something heavy	
Almost never	2 (6.2%)
Sometimes	18 (56.3%)
Often	4 (12.5%)
almost always	8 (25%)
5-Taking a bath or shower by him or herself	
Never	6 (18.8%)
Almost never	16 (50%)
Sometimes	4 (12.5%)
Often	2 (6.2%)
almost always	4 (12.5%)
6-Having aches or pains	
Never	4 (12.5%)
Almost never	8 (25%)
Sometimes	14 (43.8%)
Often	2 (6.2%)
almost always	4 (12.5%)
7- Having aches or pains	
Almost never	10 (31.3%)
Sometimes	16 (50%)
Often	2 (6.2%)
almost always	4 (12.5%)
8-Feeling tired	
Sometimes	12 (37.5%)
Often	12 (37.5%)
almost always	8 (25%)
EMOTIONAL FUNCTIONING (problems with…)	
9-Feeling afraid or scared	
Never	8 (25%)
Almost never	6 (19%)
Sometimes	12 (38%)
Often	6 (19%)
10-Feeling sad	
Never	4 (12%)
Almost never	8 (25%)
Sometimes	8 (25%)
Often	12 (38%)
11-Feeling angry	
Never	2 (6.2%)
Almost never	2 (6.2%)
Sometimes	18 (56%)
Often	6 (19%)
almost always	4 (12%)
12-Trouble sleeping	
Never	8 (25%)

Almost never	14 (44%)
Sometimes	10 (31%)
13-Worrying about what will happen to him or her	
Never	8 (25%)
Almost never	14 (44%)
Sometimes	4 (12%)
almost always	6 (19%)
SOCIAL FUNCTIONING (problems with…)	
14-Getting on with other children	
Never	10 (31%)
Almost never	10 (31%)
Sometimes	2 (6.2%)
Often	6 (19%)
almost always	4 (12%)
15-Other children not wanting to be his or her friend	
Never	12 (37.5%)
Almost never	10 (31.25%)
Sometimes	6 (18.75%)
Often	2 (6.25%)
almost always	2 (6.25%)
16-Getting teased by other children	
Never	10 (31.25%)
Almost never	12 (37.5%)
Sometimes	4 (12.5%)
Often	6 (18.75%)
17-Not being able to do things that other children his or her age can do	
Never	4 (12%)
Almost never	6 (19%)
Sometimes	16 (50%)
Often	6 (19%)
18-Keeping up when playing with other children	
Never	8 (25%)
Almost never	14 (44%)
Sometimes	6 (19%)
Often	4 (12%)
School functioning	
19-Paying attention in class	
Almost never	2 (6.2%)
Sometimes	16 (50%)
Often	10 (31%)
almost always	4 (12%)
20-Forgetting things	
Almost never	4 (12%)
Sometimes	16 (50%)
Often	10 (31%)
almost always	2 (6.2%)
21-Keeping up with school activities	
Almost never	6 (19%)
Sometimes	10 (31%)
Often	12 (38%)
almost always	4 (12%)
22-Missing school because of not feeling well	
Never	2 (6.2%)
Almost never	2 (6.2%)
Sometimes	4 (12%)
Often	18 (56%)
almost always	6 (19%)
23-Missing school to go to the doctor or hospital	
Sometimes	4 (12%)
Often	19 (60%)
almost always. ++	9 (28%)

Table 1 represents Frequency and percentages of the participants responses for the different questions in subscales in PedsQL™ 4.0 questionnaire.

The mean total scale in the whole sample is 46.9 ± 13.5, The largest total scale in the group who have children 8–12 years 50.6± 6.4. The mean physical, Psychosocial health, Emotional, social, and school functioning scale are 42.4±17.5, 49.3± 12.8, 49.3±12.8, 54.7± 12.7, 59.4± 18.5, 33.9±13.4. Most scales exceeded the minimum reliability standard of 0.70. Internal consistency reliability for the Total Scale Score (α = 0.92), Physical Health Summary Score (α = 90), Psychosocial Health Summary Score (α = 0.87), Emotional functioning score (α = 0.55), Social functioning (α = 90) and School functioning (α = 0.67).

		2–4 Years (toddler)		5–7 years (Young child)		8–12 years (child)		Total		Cronbach's alpha α
		N=2		N=20		N=10		N=32		
	N of items	Mean	SD	Mean	SD	Mean	SD	Mean	SD	
Total score	23	48.3	0.7	44.9	16.3	50.6	6.4	46.9	13.5	0.92
Physical scale	8	34.3	0	40	21.5	48.7	3.3	42.4	17.5	0.9
Psychosocial health scale	15	55.8	1.2	47.5	14.4	51.6	10.1	49.3	12.8	0.87
Emotional functioning scale	5	65	0	54.5	10.1	53	17.8	54.7	12.7	0.55
Social functioning scale	5	65	0	55.5	20.5	66	14.3	59.4	18.5	0.9
School functioning scale	5	37.5	3.5	32.5	15.7	36	9	33.9	13.4	0.67

Table 2: presents the means and standard deviations of the PedsQL 4.0 Generic Core Scales and the internal consistency for parent proxy-report.

	Physical functioning	Emotional functioning	Social functioning	School functioning
Physical functioning (r)	1	0.41	0.84	0.60
P value		0.019*	<.001*	<.001*
Emotional functioning (r)	0.41	1	0.73	0.40
P value	0.01		<.001*	.022*
Social functioning (r)	.840	0.73	1	0.61
P value	<.001*	<.001*		<.001*
School functioning (r)	0.60	0.40	0.61	1
P value	<.001*	.022*	<.001*	

Table 3: shows the Intercorrelations between and among PedsQL 4.0 Generic Core Scales subscales. Table 3 demonstrates a robust and statistically significant correlation between social functioning and all other subscales, with a Pearson moment correlation coefficient of $r \geq 0.50$ and a p-value ≤ 0.05. Additionally, a strong and statistically significant correlation was found between school functioning and physical functioning with a Pearson moment correlation coefficient of r =0.60 and p <.001, while a moderate and statistically significant correlation was observed between the emotional functioning scale and physical functioning as well as school functioning, with a Pearson moment correlation coefficient of r = 0.4 and a p-value of less than 0.05.

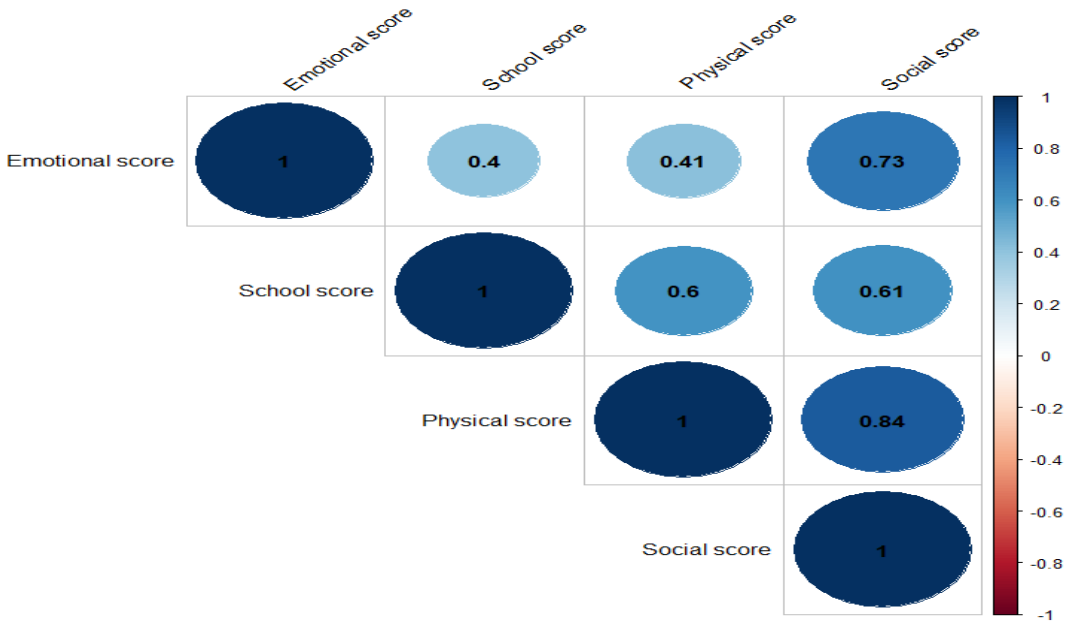

Figure 1: shows Intercorrelations between and among PedsQL 4.0 Generic Core Scales subscales, the darker blue circles denotes positive stronger correlation, the lighter blue circles less strong positive correlation (moderate)

Discussion:

A common Mediterranean hemoglobinopathy passed down the generation 90 years ago called thalassemia instigate us to investigate. Indeed, Healthcare organizations looking forward to improve patient's quality of life and find ways to evaluate. Absolutely, Quality of life is valuable, meaningful, and should be taken into consideration. Wherefore, we surveyed 32 parents of children aged 3-18 years old to investigate their quality of life using PedsQL questionnaire in North Sinai which is considered a Mediterranean region.

Those patients receiving blood transfusion monthly to treat thalassemia during a period of the research. The study population divided into (56.3%) females and (43.7%) males. A 100% response rate of the parent on the questionnaire indicate their intense to improve on quality of life of their children. The present study mean total score (46.9 ± 13.5) was lower than that of a study conducted in Egypt 2014 (63.74 ± 13.2) which indicate a lower quality of life.(36)

Per contra, it is higher than the result of a study conducted on Iranian patients, their quality of life was (12.96±2.67).(37) Qol questionnaire consisted of 4 scales and 23 items The 4 scale was Physical Functioning (eight items);Emotional Functioning (five items); Social Functioning (five items); and School Functioning (five items). In the most literature studies physical and school functioning domains were the most affected.(38,39) .And also, by comparing the category of quality of life each other's we found that school functioning, 33.9±13 is the lowest QOL score category followed by physical health quality of life 42.4±17.5 while social functioning has the best scoring 59.4± 18.5 followed by emotional functioning 54.7± 12.7.

Ali, Hongally, a study conducted in Riyadh, KSA considered that the quality of life was socially not disrupted because of the attention and support that given to the children, making them in a good social life. (40)(41)(26) This may be due to disease complications increased as children get aged, resulting in decreased feeling of Discrimination. (36) Relatively looks like a study conducted in Egypt in which school and physical functioning the most affected. (36) Another study conducted in Iran results in low physical functioning comparing to the other categories.(37)

Additionally, a study conducted to compare west bank region and Gaza show decreases in school and physical functioning (42) Moreover, Physical functioning of the present study was (58.46 ± 18.09), lower than a study conducted in Gaza and west bank (58.06) and (63.01) respectively.(42,43)

Previous study conducted in Egypt addressed low quality of life of Transfusion dependent thalassemia, and patients usually suffer from chronic repeated transfusion and hospital admission which interrupt different life aspects socially, physically, and attendances to school. (44)

In a study conducted in Egypt a transfusion dependent patient shows lower quality of life than non-transfusion dependent patient. (44) A study conducted on Patients Attending the Hematology Outpatient Clinics at Cairo University Hospital patients aged ≥17 years assessed for QoL, and the study shows that qol were compromised and intervention to improve QoL was needed .(45)Another study conducted in developing countries in which thalassemia patients' quality of life was immensely affected and stress were over their social, psychological, and emotional life also affect their career and education. (46–48)

The impact of age on quality-of-life scoring was determined in this study. It is shows as previewed in table 3 when children get older the physical health get better but emotional functioning worsen. In a study conducted in Gaza and western bank region physical and school functioning worsens by age while social functioning improved by age. as shown in table 3 there is a statistically significance correlation between social functioning and all other subscales, with a Pearson moment correlation coefficient of $r \geq 0.50$ and a p-value ≤ 0.05

Additionally, a strong and statistically significant correlation was found between school functioning and physical functioning with a Pearson moment correlation coefficient of r=0.60 and p<.001, while a moderate and statistically significant correlation was observed between the emotional functioning scale and physical functioning as well as school functioning, with a Pearson moment correlation coefficient of r = 0.4 and a p-value of less than 0.05. (49,50) Ali SS21 also observed that thalassemia patients had significantly higher scores in the social domain.(55) This finding was not consistent with studies by Pruthi, Naderi, and Ishtiaq. (48) .

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