PEDIATRIC SCIENCES JOURNAL
The Official Journal of the Pediatric Department, Faculty of Medicine, Cairo University, Egypt

Original Article

COVID-19 Lockdown Aggravated the Health-Related Quality of Life of Children with Transfusion-Dependent-Thalassemia

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Received: 28/9/2023; Accepted: 7/12/2023; Published online: 10/12/2023

Abstract:

Background: Thalassemia is the most prevalent cause of chronic hemolytic anemia and associated with high rates of morbidity and mortality. Its management is demanding, timely and multidisciplinary creating a strain on the patients, their families, and society.

Aim of the work: To study the effect of the corona virus disease of 2019 (COVID-19) pandemic lockdown on the health-related quality of life (HRQoL) of the children with transfusion-dependent thalassemia.

Subjects and Methods: The HRQoL (child self-report) and (parent proxy-report for those children) questionnaires of the Pediatric Quality of Life Inventory (PedsQL) Measurement Model were used to study the same group of 131 children with transfusion-dependent-thalassemia before and during the-COVID-19 era lockdown and compared them to 200 matched children with their parents as a control group.

Results: 67 (51.1%) males and 64 (48.9%) females, transfusion-dependent thalassemia patients were included in our study. The mean age was 8.28 ± SD3.81 (range 5-18) and 8.94 ±SD 3.78 years at initial assessment and during the lockdown respectively (p=0.0001). in the pre-COVID-19 the score of patients in all the aspects of PedsQL questionnaire was 60.4±22.8 while that of the control group was 97.3±3 (p <0.001). The mean ± SD of total PedsQL score in the patients before COVID-19 was 60.24 ± 22.8 SD and during the lockdown was 55.96±18.3 (p <0.001). The parent proxy-report for those children was lower than that of the patients (p <0.001). Before COVID-19 the least PedsQL 25.22±4.5 and 25.43±7.2 were reported by those on IV deferoxamine**,** and by older patients (13-18 years) compared to the control group of 97.3±3 (p <0.001 and p <0.00) respectively. During the lockdown the values dropped significantly as reported by the children and their parents (p<0.001).

Conclusion: Transfusion-dependent thalassemia has an alarming negative impact on all aspects of the quality of life of the affected children and their families. This straining negative aspect was accentuated by the COVID-19 lock-down. Multidisciplinary task force to address the emotional, social, and physical perception of children with transfusion- dependent thalassemia and their parents is imperative.

Level of Evidence of Study: IV (*1*)**.**

Keywords: Health-related quality of life; Transfusion-dependent thalassemia, HRQoL; COVID-19; Pediatric Quality of Life Inventory; pandemic; lockdown.

Abbreviations: COVID-19: corona virus disease of 2019; HRQoL: Health-related quality of life (HRQoL); PedsQL: Pediatric Quality of Life Inventory; QoL: Quality of life; SES: Socioeconomic status

Introduction

Thalassemia is the most prevalent cause of chronic hemolytic anemia and is associated with high rates of morbidity and mortality, creating a strain on the patients; families, society, and the government on social and economic levels (*2*, *3*). Children with thalassemia may develop health problems that increase morbidity and mortality as transfusion dependence, iron overload symptoms e.g., cardiac dysfunction, and endocrine abnormalities. Fortunately, chelation therapy prevents and may reverse the complications of iron overload (*4*, *5*). In addition, the psychological and social burden on the patient and the families are considered serious implications for the

health-related quality of life of children (HRQoL). Many factors may negatively affect these children regarding the quality of their life such as the need for regular blood transfusions and frequent hospital visits (*6*, *7*).

The Pediatric Quality of Life Inventory (PedsQL) is a modular instrument designed to measure health-related quality of life (HRQoL) in children and adolescents ages 2–18 years. The PedsQL 4.0 Generic Core Scales are multi-dimensional child self-report and parent proxy-report scales (*8–10*). Several studies demonstrate the HRQoL in children and adolescence in low-middle countries (*5*, *11–13*), but there is a paucity of data from Egypt (*14*, *15*). While the first case of corona virus disease of 2019 (COVID-19) in Egypt was confirmed on February 14th, 2020 (*16*), and the Egyptian government declared it a public health emergency on March 24th, followed by a nationwide lockdown to prevent the spread of the virus (*17*). Our aim was to study the effect of the COVID-19 pandemic lockdown on the health-related quality of life (HRQoL) of the children with transfusion-dependent thalassemia.

Subjects and Methods

This prospective cohort study was conducted in the Pediatric Hematology unit at Cairo University Children's Hospitals. Privacy and confidentiality of the participating patients and their parents were maintained. The study was approved by the Research Ethical Committee of Faculty of Medicine, Cairo University (No. N126-2021). An informed written consent was obtained from each patient or his/her guardian prior to his/her involvement. The study assessed the HRQoL in two different time frames (before COVID-19 pandemic declaration from July– December 2019, then, we reassessed the same cohort of patients and their parents during COVID-19 pandemic lockdown from August 2020- January 2021). The study complied with the Declaration of Helsinki for trials (*18*).

Participants

The study included 131 children with transfusion-dependent thalassemia and their parents. Their ages ranged from 5 to 18 years old. Patients with any associated chronic health conditions related to the disease or not (e.g., cardiac, endocrinal, etc.), and patients who had parents with any chronic disease that necessitated frequent hospital visits or psychological illness were excluded from our study. All our patients of the school age were in the school and under cover of the Ministry Health and Occupation's Insurance. Two hundred age- and sex-matched children and their parents were included as a control group in the pre-COVID-19 while, (but not during the lockdown) who were attending the hospital randomly as a follow-up of well- being or visiting the general outpatient clinics for minor illness without any chronic health problems.

Methods

Study Instruments:

The health-related quality of life assessment was performed using (Child Self-Report) and (Parent Proxy-Report for same children) questionnaires of The PedsQL Measurement Model for the Pediatric Quality of Life Inventory; according to the age range standardized models of 5-7, 8-12 and 13-18 years. Patients were asked how problematic a specific issue has been for them over the course of the previous month. Responses to the items were scored on a scale. A total score was generated which included items on physical, emotional, social, and school functioning, the greater the score, the higher the quality of life perception (*19*).

A user agreement was signed with the MAPI Research Trust, Lyon, France, before the use of the questionnaire. The following module (The Generic core scales (Standard version), for the thalassemia patients' group and the control group) was used (Request No. 67547) under the categorization of Not funded academic research, and the Arabic language was used provided by MAPI Research Trust.

During the COVID-19 lockdown, we reassessed the QoL of the enrolled patients, using the same PedsQL questionnaires, but with the exclusion of the (School functioning) domain from the assessment as the schools were temporarily closed during the COVID-19 pandemic lockdown and educational activities were virtual. The patients were following up with the doctors by social media and during any emergency they were directed to the Cairo University Children Hospital Emergency Room, the service of blood transfusion was maintained for the children during the lockdown.

For measurement of the socioeconomic status of the enrolled patients' parents, we used the new scale "Updating and validation of the socioeconomic status (SES) scale for health research in Egypt" by El-Gilany and colleagues. Socioeconomic level: was classified into very low (0-21), low (22-42), middle (43-63), and high levels (64-84) depending on the calculated score (*20*).

Clinical history and examination and laboratory results were taken. The patients were classified according to the onset of anemia whether younger or older than 2-year-old or after, age at the first transfusion whether younger or older than 1 year old, thalassemia major or thalassemia intermedia, the frequency of blood transfusion/ year whether more or less than 12 times, the frequency of hospital admission whether more or less than 3 times/ year, and serum ferritin level ≤2,500 ng/mL or more than 2,500ng/ml (*19*, *21*, *22*).

Statistical Analysis

Data were statistically described in terms of mean ± standard deviation (± SD). Comparison between the study groups was done using Mann Whitney U test for independent samples for comparing 2 groups and Kruskal Wallis test for comparing more than 2 groups. Within-group comparison of numerical variables was done using Wilcoxon signed rank test for paired (matched) samples. Correlation between various variables was done using Spearman rank correlation equation. Two-sided p-value less than 0.05 was considered statistically significant. All statistical calculations were done using computer program IBM SPSS (Statistical Package for the Social Science; IBM Corp, Armonk, NY, USA) release 22 for Microsoft Windows.

Results

The included 131 children comprised (67 (51.1%) males and 64 (48.9%) females) with transfusion-dependent thalassemia. Their mean age ± SD was 8.28 ± 3.81 (range 5-18) and 8.94 ± 3.78 years at initial assessment and during the lockdown respectively (p=0.0001). Patients were classified into 3 groups according to the used instrument: 84 (64.1%) patients ranging from 5-7 years in age, 24 (18.3%) patients from 8-12 years old, and 23 (17.6%) patients aged from 13-18 years old. The mean age of their diagnosis was at 1.75 ±SD 0.9 years, 50 (38.2%) were diagnosed below one year, 50 (38.2%) were diagnosed between 1-2 years old, and 31 (23.6%) were diagnosed above 2 years old. The mean age ± SD of the 200 control group was 9.64 ±4.24 years. The median total score of the patients' parent Socioeconomic status was 52 IQR (12), while the median total score of the controls' parent Socioeconomic status was 57 IQR (15) (p= 0.001). Both the socioeconomic status of the patients and the control group were in the middle class (63-43) (p=0.43) (*20*).

Clinical and laboratory Data:

One hundred and eighteen (90.1%) patients had hepatomegaly and 87 (66.4%) had splenomegaly. Growth retardation was the most common complication reported in 43 (32.8%) patients, followed by gall bladder stones in 29 (22.1%) patients, skeletal changes were detected in 20 (15.2%) patients, minor bleeding (epistaxis) was reported in 12 (9.1%), hepatitis C virus infection was reported in 11 (8.4%) patients which were treated successfully, and one patient (0.75%) had leg ulcers. One hundred and one (77.1%) patients had serum ferritin levels below 2500 ng/ml, and 30 (22.9%) patients had serum ferritin levels ≥ 2500 ng/ml. The mean serum level of serum ferritin was 2001.5 SD± 1633 ng/ml.

Therapeutic Interventions of the Studied Cohort:

Only 75 (57.3%) patients started their first packed RBCs transfusion before one year old and 121/131 (92.3%) patients were on chelation therapy. Those who received one drug were 92/131 (70.2%); of them 48 (52.2%) received deferasirox, 34 (37%) patients received deferiprone, and 10 (10.8%) patients received deferoxamine. While 29/131 (22.1%) patients received 2 drugs, 15 (51.7%) received deferasirox and hydroxyurea, 10 (34.5%) patients received deferasirox and deferiprone, and 4 (13.8%) patients received deferiprone and hydroxyurea. Ten (10/11) patients suffered from hepatitis C virus infections and received the treatment (Ledipasvir/sofosbuvir) with complete resolution before the enrollment in this study, while number 11 awaits receiving treatment. The patients who were admitted to the hospital ≤ 3 times/ year were 124 (94.7%), while 7 (5.3%) were admitted more than 3 times/year.

Results of the Questionnaires pre and during the COVID-19 lockdown:

There was no control group during the COVID-19 lockdown as we could not bring the same volunteers to the hospital to perform the questionnaire due to the lockdown. The scores of all aspects of the PedsQL before COVID-19 are presented in Table 1. They were all significantly lower among the thalassemia group. Those on intravenous medications and more frequent transfusions had the least scores. (Table 2). The older children with transfusion-dependent thalassemia had the least PedsQL scores, which was significantly less than that perceived by their parents. (Table 3). For every age group, the children with transfusion-dependent thalassemia had significantly less PedsQL score that was lower than their parents. (Table 4). Patients with growth retardation and skeletal changes had lower PedsQL scores than patients who are not affected (42.7± 22.9 compared to 62.8±16.2, and 49.7±22.9 compared to 59.8±21) (p =0.001, and p= 0.002 respectively). The PedsQL scales and the total score among thalassemia patients were higher pre COVID- 19) more than during COVID-19 lockdown among all age groups, with statistically significant differences in all aspects except the physical one and the total score of PedsQL of the older children. (Table 5). The thalassemia patients' parent's proxy report of PedsQL scales and the total score were higher before COVID-19 compared to during COVID- 19 among all age groups. (Table 6).

Table 1. Comparison between the scales of PedsQL questionnaire and Total Qol of the parents before – COVID- 19 lockdown among the patients with thalassemia and the control group.

	Control (Number 200)	Thalassemia (Number131)	P value
	Mean ±SD	Mean ±SD	
Total PedsQoL of children	97.3±3	60.24±22.8	<0.001
Physical aspect	97.89±3.56	58.54±26.9	<0.001
Emotional aspect	97.75±4.31	63.93±22.7	<0.001
Social aspect	97.80±4.72	63.59±20.9	<0.001
School aspect	95.85±6.48	54.92±25.4	<0.001
Total QoL of parents	97.32±3	57.60±11.3	<0.001

Table 2. The PedsQL scores of the thalassemia patients according to their clinical characteristics before-Covid-19 lockdown

			Physical Aspect	**Emotional Aspect**	**Social Aspect**	**School Aspect**	**Total Score**	**P value**
		Number	Mean± SD	Mean± SD	Mean± SD	Mean± SD	Mean± SD	
Age of diagnosis(years)	< 1	50	51.23±29.7	57.50±24.3	57.14±20.7	49.17±20.2	54.16±24.4	0.018
	1-2	50	57.12±23.9	61.94±17.75	60±18.6	50.89±27.1	57.12±18.8	
	> 2	31	57.44±25.2	63.16±21.4	63.46±19.8	53.24±24.6	59.31±21.5	
Age of 1st blood transfusion (years)	≤ 1	75	55.98±25.3	60.87±20.8	61.23±20.1	50.43±22.5	57.13±20.9	0.05
	> 1	56	55.69±27.7	62.67±23	61.56±19.7	54.44±27.1	58.58±23.3	
No. of transfusion (times / year)	≤ 12	128	70.8±9.54	63.33±11.54	80±1.2	56.67±5.8	67.7±2.22	0.97
	> 12	3	55.46±26.3	61.53±21.8	60.86±20	51.89±24.7	57.43±22	
No. of hospital admission / year	≤ 3	124	56.94±25.2	62.13±20.9	61.76±19.3	52.82±23.6	58.41±21	0.05
	> 3	7	36.46±36.9	51.67±31.9	54.17±29.6	37.50±35.3	44.94±32.9	
Serum ferritin level (ng/ml)	< 2500	101	59.78±27.7	64.85±23.3	65.54±20.8	56.14±26	61.58±23.4	0.116
	≥ 2500	30	54.38±24	60.83±20.8	57±20.2	50.83±23.6	55.75±20.9	
The (Chelation/ DM) drugs	Yes	121	56.20±26.5	61.78±22.2	61.57±20.4	52.3±24.9	57.97±22	0.001
	No	10	86.88±9.1	90±6.7	88±7.9	86±10.8	87.7±5	
Rout of administration	Oral	112	59.20±24.4	64.38±20	63.52±19	54.81±23.4	60.5±20.4	0.001
	I.V.	9	17.01±6.46	28.89±7.8	36.11±10.5	19.44±4.64	25.22±4.5	
(Chelation/ DM) Drug therapy	1 drug	92	56.79±28.6	62.76±22.7	62.12±19.5	53.62±27.9	58.31±24.4	0.001
	2 drugs	29	56.28±26.3	61.36±22.1	60.17±23.3	52.39±24.1	58.04±21.8	
	None	10	84.38±8.5	91±5.7	87±10.6	82±12.3	86.09±7.2	

DM: disease modifying (deferasirox, deferiprone, deferoxamine). IV drugs (deferoxamine).

Table 3. Comparison between Thalassemia patients, their parents, and between them regarding the scales of PedsQL questionnaire before COVD-19 according to their age group

		Physical Aspect	Emotional Aspect	Social Aspect	School Aspect	Total QoL Score
		Mean± SD	Mean± SD	Mean± SD	Mean± SD	Mean± SD
Patients	Number					
(5- 7) years Group	84	75.4±9.3	77±10.8	74.2±12.8	69.9±12.2	74.1±8.7
(8-12) years Group	24	33.59±17.9	47.50±14.5	53±15.8	34±18.9	42±15.7
(13 -18) years Group	23	15.9±6.2	28.04±11.1	32.17±11.3	15.87±5.9	25.43±7.2
P value		<0.001	<0.001	<0.001	<0.001	<0.001
Parents						
(5- 7) years Group	84	55.3±11.8	63.5±13.8	63.5±11.2	53.2±10.2	58.9±10.3
(8-12) years Group	24	49.06±9.5	57±9.2	59.5±7.9	50.25±9.8	54.60±8.3
(13 -18) years Group	23	36.82±8.9	53.48±8.3	51.30±10.4	40.65±7.6	46.9±7.6
P value		<0.001	0.002	<0.001	<0.001	<0.001
The total PedsQL score between the patients and their parents						
		Patients total QoL score		Parents total QoL score		**P value**
(5- 7) years Group	84	74.1±8.7		58.9±10.3		0.00
(8-12) years Group	24	42±15.7		54.6±8.3		0.002
(13 -18) years Group	23	25.4±7.2		46.9±7.6		0.001

The school aspect was not assessed as educational activities during the COVID-19 pandemic lockdown were virtual.

Table 4. Comparison between thalassemia patients, their parents, and between them regarding the scales of PedsQL questionnaire during COVD-19 lockdown according to their age group

		Physical Aspect	Emotional Aspect	Social Aspect	Total QoL Score
		Mean± SD	Mean± SD	Mean± SD	Mean± SD
Patients	Number				
(5- 7) years Group	84	66±8	63.4±11.1	70.5±11	66.6±6.6
(8-12) years Group	24	32.97±18	47±14.7	52.25±15.5	44.1±15.1
(13 -18) years Group	23	13.90±5.6	27.12±9.8	30.45±10	23±6.4
P value		0.001	0.001	0.001	0.001
Parents					
(5- 7) years Group	84	54.7±10.5	62.3±12.9	62.2±11	59.75±10.2
(8-12) years Group	24	48.75±9.6	56.50±9.3	58.25±9.4	54.05±7.7
(13 -18) years Group	23	36.54±9.1	53.04±8.6	50.87±10.5	45.48±7
P value	84	<0.001	<0.001	<0.001	<0.001
The total PedsQL score between the patients and their parent					
		Patients total QoL score		Parents total QoL score	**P value**
(5- 7) years Group	84	66.6±6.6		59.75±10.2	<0.001
(8-12) years Group	24	44.1±15.1		54.05±7.7	0.002
(13 -18) years Group	23	23±6.4		45.48±7	<0.001

The school aspect was not assessed as educational activities during the COVID-19 pandemic lockdown were virtual.

Table 5. Comparison between the PedsQL scales score in (Pre and during - Covid-19) lockdown among the thalassemia patients according to the age groups.

Age groups		Physical aspects		Emotional aspect		Social aspect		Total score	
		Pre (Mean ±SD)	During (Mean ±SD)	Pre (Mean ±SD)	During (Mean ±SD)	Pre (Mean ±SD)	During (Mean ±SD)	Pre (Mean ±SD)	During (Mean ±SD)
Patients	Number								
(5-7) years	84	75.4±9.3	66±8	77±10.8	63.4±11.1	74.2±12.8	70.5±11	74.1±8.7	66.6±6.6
P value		<0.001		<0.001		0.004		<0.001	
(8-12) years	24	33.59±17.9	32.97±18	47.50±14.5	47±14.7	53±15.8	52.25±15.5	42±15.7	44.1±15.1
P value		0.257		0.317		0.317		0.257	
(13-18) years	23	15.9±6.2	13.90±5.6	28.04±11.1	27.12±9.8	32.2±11.3	30.45±10	25.43±7.2	23±6.4
P value		1		1		1		1	
All groups		58±54.26.9	52.17±22.7	63.93±22.7	54.69±17.9	62.07±22.4	60.95±19	62.07±22.4	55.96±18.3
P value		<0.001		<0.001		0.003		<0.001	

The school aspect was not assessed as educational activities during the COVID-19 pandemic lockdown were virtual.

Table 6. Comparison between the PedsQL scales score in (Pre and during - Covid-19) lockdown among the thalassemia patients and their parents according to the age groups.

Age groups		Physical aspects		Emotional aspect		Social aspect		Total score	
		Pre (Mean ±SD)	During (Mean ±SD)	Pre (Mean ±SD)	During (Mean ±SD)	Pre (Mean ±SD)	During (Mean ±SD)	Pre (Mean ±SD)	During (Mean ±SD)
Parents	Number								
(5-7) years	84	55.3±11.8	54.7±10.5	63.5±13.8	62.3±12.9	63.5±11.2	62.2±11	58.9±10.3	59.75±10.2
P value		0.152		0.001		<0.001		<0.001	
(8-12) years	24	49.06±9.5	48.75±9.6	57±9.2	56.50±9.3	59.5±7.9	58.25±9.4	54.60±8.3	54.05±7.7
P value		0.157		0.157		0.059		0.026	
(13-18) years	23	36.82±8.9	36.54±9.1	53.48±8.3	53.04±8.6	51.30±10.4	50.87±10.5	46.9±7.6	45.48±7
P value		0.623		0.705		0.157		0.763	
All groups		51.07±13	50.62±12.	60.76±13	59.85±12.3	60.75±11.5	59.62±11.4	57.54±11.3	56.71±10.6
P value		0.178		0.001		<0.001		<0.001	

The school aspect was not assessed as educational activities during the COVID-19 pandemic lockdown were virtual.

Discussion

Our study showed that patients with thalassemia had significantly lower quality of life (QoL) scores in all aspects of the PedsQL score than their matched healthy peers in before the-COVID-19 pandemic. The physical score and school functioning were the lowest among the PedsQL aspects. Also, many patients reported that they got too tired and were unable to tend to the routine daily chores. Many studies reported the same results, in developed and low/middle-income countries (*23*, *24*), with the highest impact on low- and middle-income countries such as Egypt and Thailand compared to their North American counterparts (*14*, *19*, *25*). Another report from Pakistan found that patients suffered from psychological stress, physical impairments caused by growth retardation, and chronic illness (*21*). Hospital visits to receive regular transfusions, performing blood tests, and treatment the complications are known to have a negative impact on the school functioning domain of patients' HRQoL (*11*, *13*).

We found a negative correlation between the age of the patient and his total QoL score, as the highest score in all aspects was among the age group (5-7) years old. Several studies attributed the higher scores at younger ages to the recent onset of the disease, which led to less iron overload and thus fewer consequences (*21*, *26*). Additionally, as the patient matures, he becomes aware of the nature of his disease, undergoes more repeated blood transfusion visits, school absence, bullying at school, and obvious morphological changes result in poor self-esteem, expression of negative thoughts toward their chronic illness, leading to social withdrawal, and low social performance (*27*, *28*). Nevertheless, other studies contradicted our results and reported that age was not an effective factor in poor scoring in HRQol. It was explained that this risk factor was overcome by the strict arrangements taken for patients' comfort and health, better adjustment, and coping with their illness than the young patients (*13*, *19*).

In our study, there was a striking difference in the perception of illness between parents and older children, as the parents-proxy reports were with a better HRQoL than their children (except for those less than 7 year-old). Interestingly it was found lower than that reported in Upper Egypt, where parent-proxy reports were almost like the patient self-reports. This can be attributed to strong family support ties in upper Egypt (*14*). Another possible explanation of our findings is that even with the increase in parents' awareness of the chronicity of their children's disease, still there is a lack of a enough effective supportive environment that helps older patients to reduce their anxiety levels to expand their social network and decrease the effect of the negative behavioral and physiological reactions. Further studies are necessary to determine whether parent-child agreement is influenced by additional variables, such as the parent-to-child relationship, depression, faith or otherwise (*29*). We did not include data about the patient sharing in support groups, hence we are not aware if the support has an impact on their health-related quality of life, yet effect of support needs to be studied. It is noteworthy that the age of diagnosis was an influential factor in HRQoL in our study. The enrolled patients who were diagnosed older than 2 years had significantly higher total HRQoL scores than those who were diagnosed younger, which is congruent with previous studies (*19*, *28–31*). It might be attributed to lesser duration of suffering.

We found a negative correlation between the serum ferritin level and the total PedsQL score of the patients. Despite being an inconsistent finding between different countries, it seems that the better control of ferritin comes with less fatigue, lesser complications, preservation of liver function and better metabolism (*13*, *19*, *21*, *30–33*). Accordingly, we found that higher scores were

recorded among patients who had not received chelation therapy yet -their serum ferritin level was below (2500ng/ml)- and those on one oral iron chelation therapy compared to those on combined oral and subcutaneous therapy. This better score might be explained by the lesser exposure to the side effects from chelation treatment such as nausea, vomiting, and pain at the injection site affect QoL (*31*). It is imperative to note that chelation therapy is the standard of care to prevent excessive accumulation of iron in body organs, and ferritin levels are inversely correlated with survival and QoL, which stresses the significance of chelation therapy importance (*34*, *35*). We advise against delaying iron chelation therapy once indicated.

The lockdown of COVID-19 was devastating to our studied cohort, but not uniformly across the ages of the studied children. It seems that social interaction is responsible for a bigger portion of quality of life among our studied cohort. Others reported that the children with transfusion-dependent thalassemia found the lockdown an excuse to express their reluctance to attend their regular blood transfusion sessions (*36*). Yet, the lockdown came with less school challenges and more emotional support from immediate family contacts (*37–39*).

Transfusion-dependent thalassemia is life threatening and compromises quality of life. Treatment of transfusion-dependent thalassemia should include other aspects to preclude this exceptionally poor quality of life among them. Egypt has high prevalence of transfusion-dependent thalassemia, and one of its goals should be prevention, by screening of the high risk, premarital and families with index cases. Egypt has successfully organized eradication of bilharziasis, hepatitis C virus, poliomyelitis etc. (*40–42*). Egypt should enforce legislations to aim for eradication of thalassemia through strict pre-marital, high risk (*43*) and periconceptional testing and counselling among the families known to have genetic mutations.

As for now, until the eradication era ensues, early screening, prompt diagnosis and early bone marrow transplantation to reduce this suffering.

Conclusion

Transfusion-dependent thalassemia significantly compromises quality of life of children. The COVID-19 pandemic lockdown had a negative impact on their already compromised quality of life. There is a huge room for improvement of management of children with transfusion-dependent thalassemia to secure their emotional, social, and physical perception functioning as well as their parents. Egypt has high prevalence of transfusion-dependent thalassemia, and one of its goals should be prevention, by screening of the high risk, premarital and families with index cases. Until then prompt diagnosis and bone marrow transplantation are essential to provide a better alternative for children with transfusion-dependent thalassemia.

Author Contributions:

All authors contributed to the study conception and design. Material preparations were performed by DAE, IY, HF, NA. Data analyses were performed by HF and NA. The first draft of the manuscript was written by D. AE and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

FUNDING

Authors declare there was no extramural funding provided for this study.

CONFLICT OF INTEREST

The authors declare no conflict of interest in connection with the reported study. Authors declare veracity of information. The datasets generated and/or analyzed for this study are available from the corresponding author upon reasonable request.

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