Psychosocial Aspects of Children with Thalassemia in Mosul City.

Abstract

Background: Thalassemia is a widespreadheritable disease in Mediterranean region, the assessment of psychological and social status of thalassemicchildren is an important issue.

Objectives: The main aim is to assess psychosocial statusof children with thalassemia and to find out the association between some demographic characteristics and psychosocial aspects.

Methodology: A cross-sectional study of (101)randomly selected thalassemic children.The study was conducted at Al-Hadbaa Specialist Hospital for blood diseases and bone marrow transplantation ,Mosul City, Iraq for the period from 1st November 2023 to 5th January 2024.In order to collect the required data, a questionnaire was developed based on the standards of the pediatric quality of life Scale(PedsQoL).

Results: shows that the largest proportion of samples belong to the age group (9-12) years and the highest percentage of the study sample is female (50.5%).Regarding education, the table presents that the highest percentage of patients are student (67.3%). The table also shows that (65.3%) of patients have family history of thalassemia.For the number of blood transfusion, the highest percentage was (every 3 weeks) to be (59.4%) . The mean+SD emotional domain score was 1.8733±0.602, social domain score was 1.2436±3.55.

Conclusion: The present study indicates that psychosocial aspects were range between moderate for emotional functioning and good for social functioning.And there is significant association between some demographic variables and psychosocial functioning of thalassemic children.

Recommendations: The current study recommended to provide psychological and social support units for thalassemic children to help them to adapt with the disease by reducing negative thoughts about themselves and building a positive self-image.

Keywords: Psychosocial Aspects, Children, Thalassemia.

Introduction

Thalassemia is one of the most common hereditary blood disorders is caused by absence or reduced synthesis of one or more of the normal globin chains[1].There are two types of thalassemia, depending on the location of defect in globin are alpha-thalassemia and beta thalassemia[2]. According to the World Health Organization (WHO)(2018), approximately 1.5% of the world's population is a carrier or heterozygous for thalassemia, and 12% or more of newborns with thalassemia need blood transfusions[3].Nearly 56,000 pregnancies worldwide result in thalassemia. Around 3500 of them pass away during infancy due to hydrops fetalis, while roughly 30,000 are impacted by β-thalassemia[4].Thalassemia is more prevalent in EastMediterranean region, Southeast Asia and India[5].Iraq is among the nations where 6–10% of people suffer from hemoglobinopathies, thalassemia being the most common[6].

Thalassemia symptoms are mainly caused by a genetic mutation that affects the production of hemoglobin, a protein in red blood cells that carries oxygen throughout the body, resulting in anemia and related symptoms such as fatigue, weakness, pale skin, and other complications. The severity of the illness determines how bad the symptoms are [7]. A person who has thalassemia trait may not have any symptoms at all or may have only mild anemia, while a person with thalassemia major may have severe symptoms and may need regular blood transfusions[8].The diagnosis process begins in the clinic, where physical examination and history-taking are madefor collecting signs and symptoms. Laboratory testing is an essential requirement in order to confirm the diagnosis. The range of laboratory tests available for the diagnosis of beta thalassemia includes advanced genetic testing as well as standard blood tests like peripheral smears, complete blood counts, iron studies, and hemoglobin analyses[9]. Treatment for thalassemia varies depending on the kind and severity of the disease. Some need no treatment at all, or only sporadic care. Others need continuous counseling. Blood transfusions are a typical part of thalassemia treatment. Thalassemia may be fatal if the proper treatment is not

given[10]. Regular blood transfusion and the use of iron-chelating agents have been the mainstay of supportive treatment in thalassemia[11]. Because of the advancement of newtherapies over the last few decades, the prognosis and survival rates of thalassemia patients have significantly improved[12].

Possible Health complications of thalassemia are mostly found in thalassemia major and intermediate [13]. Patients with thalassemia often face serious complications such as endocrine disorders, cardiac arrhythmia, liver disease, infections, and heart failure. Thesecomplications affect the patients' physical functioning as well as their emotional, social, and academic achievement[14].Psychological and social influences will greatly affect school-age thalassemic children in the form ofsocialization disorders and disorders with social groups[15] .Patients with thalassemia have social life limitations due to sentiments of shame or denial, uncertainty about the disease's prognosis, fear of stigma, or impending death thalassemic patients experience stress, anxiety and depression [16].Children with thalassemia experience social isolation, bad life perceptions, guilt feelings, elevated anxiety, and low self-esteem[17].

Thalassemia children may experience social disorders such as social anxiety, difficulties in forming and maintaining relationships, feelings of exclusion or isolation, and challenges in participating in social activities due to their medical condition. These social disorders can impact their mental health and overall well-being[18].Children with thalassemia perceive physical differences in themselves and others, such as abnormalities in the face, lack of growth, or malformations of the bones, or incapacity, such as exhaustion, to carry out daily activities and all these could lead tonegative thoughts as well asemotional and social problems[19].Despite these limitations, it is important for thalassemia children to receive support from their families, friends, teachers, healthcare providers to help them overcome these challenges and lead fulfilling social lives[20].

The most effective way to decrease complications of thalassemia patients is by increasing knowledge, attitude and practice awareness of these patients and their

parents about the disease and its management, which will result in a positive impact in their quality of life[21].

Methodology:

A cross-sectional study was carried out in Mosul City at Al-hadbaa specialist hospital from 1st November 2023 to 5th January 2024 on children with thalassemia . All children were randomly selected after obtaining formal consent from their parents of the participating children. Inclusion criteria were age between 3-12 years, children with thalassemia who visited the Al- hadbaa specialist hospital. Exclusion criteria involved age<2 years or >12years ,and patients who participated in the pilot study were excluded from the final analysis. In order to collect data we used the Arabic version of the developed PedsQoL questionnaire version 4.0 .The PedsQL model is primarily utilized in pediatrics because it is so simple to understand. Two tools were used to collect data, Part one includes socio-demographic data sheet and part two include psychosocial (emotional and social) aspect items .In patients less than 8 years, the questionnaire was filled by the child's parents . In older children ,the questionnaire was filled by the child during interview. An instrument was conducted through the use of five point Likert Scale the rating was range from 1-5 as follows: Never=1, Almost=2,Sometimes=3, Often=4, and always=5.The validity of tools of the study and their content were verified by presenting them to a panel of fifteen (14) experts from different specialties.Cut off points for PedsQL models' scores for each domain include: Good life quality = (0-1.7); Moderate life quality = (1.8 -3.6); Poor life quality = (≥3.7).Alpha correlation coefficient was used to determine the questionnaire's internal consistency. The internal consistency of the questionnaire in this study was(r =0.873).The data of the present study are analyzed through the use of Statistical Package of Social Sciences (SPSS) version 26, performed through the use of descriptive statistical data analysis approach.

Results:

Table (1): Distribution of the study sample by theirdemographical characteristic.

Variables		F	%
Age	(3-5)	31	30.69
	(6-8)	29	28.71
	(9-12)	41	40.59
Total		101	100
Gender	Male	50	49.5
	Female	51	50.5
Total		101	100
Residence	Urban	71	70.3
	Rural	30	29.7
Total		101	100
Education	Student	68	67.3
	Non-student	33	32.7
Total		101	100
Family history of thalassemia	Positive	66	65.3
	Negative	35	34.7
Total		101	100
Is there a consanguinity between parents	Yes	71	70.3
	No	30	29.7
Total		101	100
Frequency of blood transfusion	Once a week	0	0
	Every 2 weeks	17	16.8
	Every 3 weeks	60	59.4
	Once a month	24	23.8
Total		101	100
Splenectomy undergone	Positive :	9	8.9
	Negative	92	91.1

Total	101	100

Table (1) shows that the majority of children's age was ranged (9-12) years which represents (40.59%). The results shows that the highest percentage of sample (50.5%) reported the females more than males .It shows that the highest percentage of subjects (70.3%) was living in urban area and regarding the education, the study results revealed that (67.3%) was students. Regarding family history of thalassemia,the highest percentage was positive to be (65.3%).the table shows the majority of participants came from parents who were married consanguineously (70.3%). Regarding blood transfusions, the highest percentage was (once every 3 weeks) to be (59.4%). Regarding splenectomy undergone the table shows that the majority of children (91%) reported negative.

Table (2): Classification of socio-economic classes for children according to Kuppuswamy's Score.

class	Total score	F	%
Upper class	26-29	0	0
Upper middle class	16-25	4	4
Lower middle class	11-15	33	32.7
Upper lower class	5-10	63	62.4
Lower class	<5	1	1

Table (2) shows that the socio-economic status for participants are upper lower class according to Kuppuswamy's scale with percentage of (62.4%).

Table (3): Children's' responses to emotional functioning questions.

Items	Rating	F	%	Mean	Sd.	RANK
Feeling afraid	Never	56	55.4	1.9208	1.23841	**3**
	Rarely	15	14.9			
	Sometimes	19	18.8			
	Often	4	4			
	Always	7	6.9			
Feeling sad	Never	30	29.7	2.2475	1.013963	**2**
	Rarely	26	25.7			
	Sometimes	37	63.6			
	Often	6	5.9			
	Always	2	2			
Having sleeping troubles	Never	73	72.3	1.4752	0.92297	**4**
	Rarely	16	15.8			
	Sometimes	6	5.9			
	Often	4	4			
	Always	2	2			
Having any concerns about what would happen in the future	Never	42	41.6	2.2574	1.23817	**1**
	Rarely	13	12.9			
	Sometimes	27	26.7			
	Often	16	15.8			
	Always	3	3			
Do you feel worried while waiting for the medical examination and analysis ?	Never	76	75.2	1.4653	0.93343	**5**
	Rarely	11	10.9			
	Sometimes	7	6.9			
	Often	6	5.9			
	Always	1	1			

General mean	1.8733

Table (3) shows that the item (Having any concerns about what would happen in the future) is the highest level ,while the item (Do you feel worried while waiting for the medical examination and analysis) is the lowest level .

Table (4): Children's' responses to social functioning questions

Items	Rating	F	%	Mean	Sd.	RANK
do you have problem with getting on with other children?	Never	96	95	1.0792	0.93200	**4**
	Rarely	3	3			
	Sometimes	1	1			
	Often	1	1			
	Always	0	0			
Other children not wanting to be his or her friend	Never	100	99	1.0198	0.19901	**5**
	Rarely	0	0			
	Sometimes	1	1			
	Often	0	0			
	Always	0	0			
Getting teased by other children	Never	95	94.1	1.1089	0.46693	**3**
	Rarely	2	2			
	Sometimes	3	3			
	Often	1	1			
	Always	0	0			
Not being able to do things that other children his or	Never	56	55.4	1.5644	0.71296	**1**
	Rarely	34	33.7			
	Sometimes	10	9.9			
	Often	1	1			

her age can do	Always	0	0			
Do you find difficulty in playing with other children ?	Never	66	65.3	1.4455	0.67045	**2**
	Rarely	25	24.8			
	Sometimes	10	9.9			
	Often	0	0			
	Always	0	0			
General mean				1.2436		

Table (4) shows that the statement (not being able to do things that other children his or her age can do) is the highest level ,while the statement (other children not wanting to be his or her friend) is the lowest level .

Table (5) Statistics relationship between emotional functioning and socio-demographic variables

Correlation type	socio-demographic variables	Correlation indicators	emotional domain
Spearman's rho	Age	Correlation Coefficient	.063
		P-value	.533
	Gender	Correlation Coefficient	-.053
		P-value	.598
	Residence	Correlation Coefficient	-.051
		P-value	.610
	Education	Correlation Coefficient	-.147
		P-value	.143
	Family history of thalassemia	Correlation Coefficient	.009
		P-value	.929
	Is there a consanguinity	Correlation Coefficient	-.009

	between parents	P-value	.932
	Frequency of blood transfusion	Correlation Coefficient	**-.686**
		P-value	**.034**
	Splenectomy undergone	Correlation Coefficient	.014
		P-value	.891
	Father's educational Level	Correlation Coefficient	-.116
		P-value	.246
	Mother's educational Level	Correlation Coefficient	-.034
		P-value	.735
	Profession as head of a family	Correlation Coefficient	**-.593**
		P-value	**.045**
	Monthly household income	Correlation Coefficient	-.110
		P-value	.272

Table (5) showed the there is an inverse correlation between the frequency of blood transfusions and emotional functioning for child , in terms of the value of the correlation coefficient, which reached (-0.686). This correlation is significant at P-value less than (0.05).

There is an inverse correlation between the profession of the head of the family and the child's emotional performance , in terms of the value of the correlation coefficient, which reached (-0.593). This correlation issignificant at P-value less than (0.05).

Table (6) statistics relationship between social functioning and socio-demographic variables

Correlation type	socio-demographic variables	Correlation indicators	social domain
Spearman's rho	Age	Correlation Coefficient	.105
		P-value	.295
	Gender	Correlation Coefficient	-.075
		P-value	.454
	Residence	Correlation Coefficient	.011
		P-value	.916
	Education	Correlation Coefficient	-.124
		P-value	.216
	Family history of thalassemia	Correlation Coefficient	-.032
		P-value	.749
	Is there a consanguinity	Correlation Coefficient	.012

	between parents	P-value	.903
	Frequency of blood transfusion	Correlation Coefficient	-.028
		P-value	.782
	Splenectomy undergone	Correlation Coefficient	.015
		P-value	.885
	Father's educational Level	Correlation Coefficient	**.608**
		P-value	**.036**
	Mother's educational Level	Correlation Coefficient	-.092
		P-value	.360
	Profession as head of a family	Correlation Coefficient	-.020
		P-value	.841
	Monthly household income	Correlation Coefficient	.069
		P-value	.491

Table (6) appeared that there is a direct correlation between the father's educational Level and the child's social functioning at P-value less than (0.05).

Discussion

The study's findings were based on the study's objectives. Analysis of demographic characteristicsshowed that the majority of patients (40.59%) were within age group (9-12) and regarding gender, more than half of participants (50.5%)were female . These findings agree with a study results stated that the majority of patients were within age group (10_12)[22].The results also supported by another study that showed that the highest percentage was female[23].Regarding to the resident, the majority of participants(70.3%) were from urban areas.These findings agree with a study revealed that the majority of patients were from urban areas[24]. The results showed that the highest percentage of participants(67.3%) were students. Another study also revealedthat the most of children were students[25].Concerning family history of thalassemia, the majority of participants(65.3%) reported positive ,These findings consistent with a previous study that stated that the majority of patients had history of thalassemia[26].The results showed that the highest percentage of participants(59.4%) received blood transfusions every 3 weeks. These findings agree with a study results that appeared that most of patients received blood transfusions every three weeks[27].Concerning splenectomy undergone the majority

of participants (91.1%) reported negative .This result agree with a study results that appeared that the highest percentage of patients didn't undergo splenectomy[28].

Regarding socioeconomic status,table(2) showed that the majority of participants (62.4%) are upper lower class according to Kuppuswamy's scale.This finding agree with another study resultthat found that the most of the participants were from lower socio-economic status[29]. Also this result is supported by a study conducted by Safdar et al.,(2017) which stated thatPoor families and low-income groups had higher rates of thalassemia [30].

In emotional functioning, the findingsappeared that the statement(having any concerns about what would happen in the future) comes in the first rank while (do you feel worried while waiting for the medical examination and analysis) is the last rank. Thalassemia affects patients and causes variety of emotional issues such as sad, depression,and fear of future .small percentage of participants had worry while waiting for medical examinations, these may be regarding to fear of painful procedures such as: injection. These findings agree witha study resultsthat revealed that most of children with thalassemia suffer from fear, depression, and anxiety about the future[31].The present study also supported by another study that reported children with thalassemia suffer from emotional disorders as well as behavioral issues like worry, anxiety, and sleeplessness[32] .The table showed that general mean of emotional functioning (1.87) indicates that patients have a moderate quality of life in their emotional performance .

In social functioning, the findings showed the statement (not being able to do things that other children his or her age can do) is the first rank while (other children not wanting to be his or her friend) came in the last rank. Thalassemia causes anemia and exhaustion which impair child's capability to play or get on with other children. These results consistent with a study results appeared that thalassemia affects children's capability to manage effectively their everyday activities[33].The table showed that general mean of social functioning (1.24) indicates that patients have a good quality of life in their socialperformance .

It appear from table (5)that there is inverse correlation between patient's emotional domain and frequency of blood transfusions .This means that by increasing the number of times blood is taken, the child's emotional performance decreases.This results was supported by another study which stated that increasing blood transfusions affects emotional performance of patients[34].Also the results showed inverse correlation between emotional domain and Profession as head of a family .This means that the more responsibility the father has, the less emotional functioning the child will have.These findings was supported by a study result that found that parent's employment status influence quality of life for thalassemic children[35].

The study results revealed that there is a direct correlation between child's social functioning and father's educational level at p-value less than 0.036.This means that the higher the father's academic achievement, the greater the child's social performance, these finding congruent with the study by Hadeel et al., (2016) which showed that increasing the father's academic achievement increases the child's social performance[36].Table (6).

Conclusion

The present study aimed to assess psychosocial functioning of thalassemic children in Mosul City. The majority of participants were within age group (9-12) and the highest percentage was living in urban areas.The majorityof participantswere studentsand the socioeconomic status for participants was upper lower class.(Table 2).Most children have a history of thalassemia. The present study indicates that psychosocial aspects were range between moderate for emotional functioning and good for social functioning. The study results showed statistical differences between some socio-demographic data and psychosocial functioning for children with thalassemia.

Limitations and recommendations

There was difficulty in collecting data due to the bias of society, which is strict in revealing the secrets of chronic diseases.The current study recommended to provide psychological and social support units for thalassemic children to help them to adapt with the disease by reducing negative thoughts about themselves and building a positive self-image.Social media should highlight thalassemia by providing people with information about the disease and the cause of its transmission.Educational programs for parents about thalassemia to increase their knowledge about thalassemia management.

Ethical Approval:

As per international standards or university standards written ethical approval has been collected and preserved by the author(s).

Consent

As per international standards, parental written consent has been collected and preserved by the author(s).

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