Assessment The Quality of Life of Thalassemic Major Children in Duhok City

تقييم نوعية الحياة لدى الاطفال المصابين بالنوع الاكبر من الثالاسيميا في مدينة دهوك

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الخلاصة

خلفية البحث: الثلاسيميا هو إضطراب وراثي يمكن الوقاية منه يتميز بتكوين الهيموغلوبين غير الطبيعي و يؤدي الى تكسر كريات الدم الحمراء بشكل مستمرمدى الحياة. لذلك الإهتمام بنوعية حياة هؤلاء الأطفال ضروري جدا .

الهدف: تقييم نوعية الحياة لدى الأطفال الذين يعانون من فقر دم البحر اللابيض المتوسط الأكبر في مركز زين لأمراض الدم وأورام الأطفال في مدينة دهوك.

المنهجية: أجريت دراسة وصفية مستعرضة في مركز زين لأمراض الدم وأورام الأطفال في مدينة دهوك للفترة من ١٥ كانون الثاني ولغاية ٢٥ أيار ٢٠١٧ لتقييم نوعية حياة الأطفال الذين يعانون من فقر دم البحر اللابيض المتوسط. وإيجاد العلاقة بين جوانب نوعية حياة هؤلاء الأطفال والصفات الديموغرافية والإجتماعية لهم.أختيرت عينة من ٨٨ مريض مصاب بفقر دم البحر اللابيض المتوسط الاكبر الذين تتراوح أعمارهم بين ٥-١٨ سنة ،الذين يراجعون مركز زين لأمراض الدم وأورام الاطفال في مدينة دهوك من خلال إستخدام إستبيان جرد جودة حياة الأطفال(٤.٠)والذي يتكون من ٢٣ فقرة أشتملت على محاور لقياس الأداء الفسلجي الذي يحتوي على (٨)فقرات والأداء العاطفي الذي يحتوي على (٥)فقرات والأداء الإجتماعي الذي يحتوي على (٥)فقرات والأداء المدرسي الذي يحتوي على (٥)فقرات.

النتائج:أظهرت نتائج الدراسة وجود علاقة ذات دلالة إحصائية بين جميع جوانب نوعية الحياة وبعض المتغيرات مثل (التعليم والتاريخ العائلي ومستوى الدخل وتكرار نقل الدم وتاريخ إستئصال الطحال) وكذلك أظهرت نتائج الدراسة أنه لاتوجد علاقة بين جميع المجالات وبعض المتغيرات من الجنس والعمر.

الإستنتاج :استنتجت الدراسة أن نوعية الحياة أفضل بالنسبة للذكور مقارنة بالاناث.

التوصيات: ينبغي أن تضع السلطات خططا لتحسين نوعية الحياة لدى هؤلاء المرضى حيث إن التشخيص المبكر والزيارات المنتظمة والدعم المالي والتعليمي يعتبر من العوامل الرئيسية لتحسين نوعية حياة هؤلاء الأطفال بشكل عام وكذلك يوصي الباحث بإجراء المزيد من الدراسات على عينات كبيرة.

ABSTRACT:

Background: Thalassemia Major is a preventable genetic disorder characterized by abnormal hemoglobin synthesis and needs long life blood transfusions. Therefore, attention to the quality of life of these children is very necessary

Objective: Assess the quality of life among children with thalassemia major.

Methods: A descriptive cross sectional study was conducted at Jeen pediatric hematology and oncology center in Duhok city for the period from Jan. 15th to May 25th. 2017 to assess quality of life of children suffering from Thalassemia Major, and finding a You mention to finding the relationship between domain but in result to applied differences between domains of quality of life and socio-demographic variables. Eighty-eight children randomly selected between ages (5–18 years) were enrolling in the study who is reviewing Jeen pediatric hematology and oncology center in Duhok city. Information were collected through the use Peds QL 4.0 generic core scale questionnaire, which included physical domain (8) items, emotional domain (5) items, social domain (5) items, and school domain (5) items.

Results: The results of the study showed that there were statistically significant correlation between the all domains of quality of life and some variables like education, family history, income level, frequency of blood transfusion, history of spleenectomy, and non-statistically significant correlation of some variables like age and gender ,

Conclusion: The quality of life scores were best for boys as compared to girls.

Recommendations: The authorities should develop plans to improve quality of life of these patients. Whereas early diagnosis, regular visiting, financial and education support are the major factors of intervention to improve the overall quality of life of these children, the researcher also recommends conducting further studies on large samples.

Keywords: Assessment, Thalassemia Major, Quality of life.

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Introduction:

Thalassemia is a genetic blood disorder which can deadly if not remedied accurately. It is distinction by no or low production of alpha or beta globin chains which form part of the hemoglobin makeup in the red blood cells [1].Treatment of thalassemia includes uniform blood transfusion, iron chelation therapy, and suitable treatment of comorbidities[2].

Children with thalassaemia appear well at birth but develop anemia that becomes progressively worse due to the partial or total absence of hemoglobin[3].

Consequently, any performingfor carefulness to children and adolescents is a step toward make of the most meaningful structure and the best social surroundings of the future [4].Depending on the world health organization (WHO), Thalassemia is one of the greatest prevalent chronic genic disorders among 60 nations in the world, and it influence on 100000 children's activity around the world each year [5].The influences of thalassemia on physical wellness can lead to physical distort, growth blocking, and postponed maturity [6]. The puzzles cited do not only impact patients' physical employment but also their emotional employment, social employment and school employment, conductive to weaken health-related quality of life (HRQOL) of the patients [7].

These formalisms led to a growth in the life prospect of thalassemic children[8]. Thus, accent effect of confirm quality of life in children with thalassemia[9]. At the present time, life anticipation in patients with thalassemia has intensified and mortality rate has importantly reduced with the help of obtainable therapies and multiple reports around the world[10]. Presently, notion of quality of life (QoL) significantly appoint health care delivery for these patients [11]. Despite, morbidity and mortality of the thalassemia major significantly has lowered in the light of contemporary medical management, nevertheless, it could affect various situations of patients' lives. Some appearances of thalassemia major and its related complications are expecting to influence on the QOL [12].

Thalassemia is a chronic illness that may not esteemed as irrevocable illness that it requires modify to daily living activities because of its long life cure and care to insufficient its impacts on the child's physical, psychological and cognitive development through early childhood that may cause functional or social restrictions or lower effects on quality of life during the middle childhood particularly school age period, during this age becomes progressively more independent and has a raised appreciation about his condition and he can share in certain appearances of his care[13].

Objectives:

1. Assess the quality of life among children with thalassemia major through domain's (physical, Emotional, social, and School).
2. Find out the association between children's QOL and socio-demographic characteristics of children.

Patients and Methods:

A cross-sectional study was proceed during the current study from the time January to May, 2017 at Jeen pediatric hematology and oncology center in Duhok city in order to assessment of quality of life of children undergo Thalassemia Major. The study was perform among patients who attendance Jeen pediatric hematology oncology center.

Children misery from Thalassemia Major, uniformity attending the clinic and whose parents' agree for the study composite the inclusion criteria, regularly attending the center and qualified age between (5–18 years) diagnosed and recorder for treatment and follow-up for Thalassemia Major were registered in the study.

Exclusion criteria are children less than 5 years and more than 18 years. The total study population was 88 patients' randomly selected eligible patients and all patients were interviewed. Verbal consent was obtained from all patients.

Study tool "questionnaire" was validated by a number of referees and based on literature review when developed by the researcher to ensure culture & language appropriateness. After the arrangement of information obtained from referees, the tools of the study consisted of two parts:

Part I of the questionnaire contained questions regarding the demographic data (age, gender, education, and family history of thalassemia, level of income, history of splenectomy and frequency of blood transfusions).

PartII of questionnaire involved Peds QL 4.0 generic core scale developed by Varni et al. (2006)[14] was used for assessing the quality of life of the children. This 23-item scale was used to measure the core dimensions of health that is physical, emotional and social, as well as school functioning with developmentally appropriate forms for ages 2–18 years. Each item is on 5-point rating scales from (0 to 4), labeled "Never/Almost never/Sometimes/Often/ almost always". To test the reliability of the questionnaire, the questionnaire was administrated to (10) children between period 25th December 2016 to 14th January 2017., after a period of (21) days, the same questionnaire was administrated to the same group to find out the correlation between the scores of pre and post test. Pearson's Coefficient Correlation was used. The results were (Physical r=0.975, Psychological r= 0.889, Social r=0.647, Environment r=0.873) for all domains respectively. All results were significant at (p. <0.01)

Statistical analysis:

Percentages and frequency used to calculate the description of the sample.
Correlation coefficient used for fixing the stability of the tool restrictions study.
Chi-square test was used to determine the correlation between the scores of domains & variables were considered significant when P<0.01.

RESULTS:

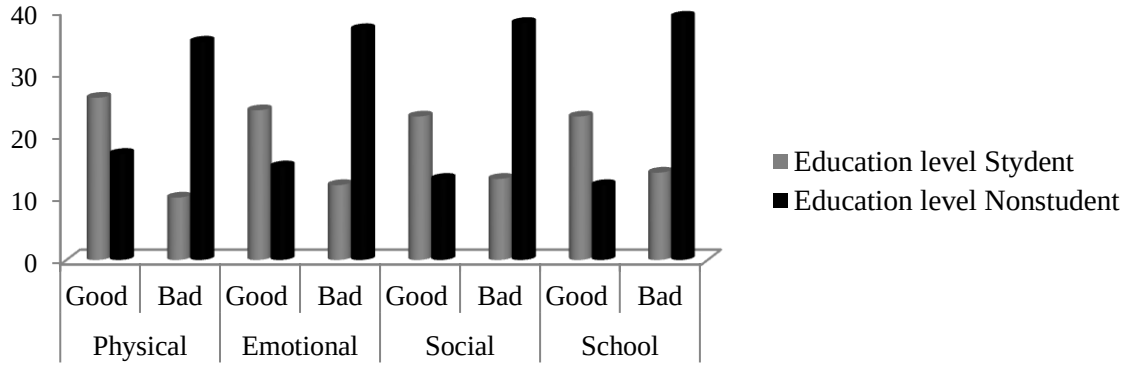

Figure (1) Effects of education level on quality of life scores.

Figure (1) shows that there were significant associations in all domains of quality of life with regard to the education level.

Table (1): Socio-demographic characteristics of the children

Variables	Characteristics	No.	%
Age (Year)	5- year	22	25.0
	10- year	40	45.5
	15- year	26	29.5
Gender	Male	53	60.2
	Female	35	39.8
Education	Student	36	40.9
	Non-Student	52	59.1
Family history	Positive	44	50.0
	Negative	44	50.0
Income level	Low	33	37.5
	Moderate	45	51.1
	High	10	11.4
History of splenectomy	Positive	40	45.5
	Negative	48	54.5
Frequency of blood transfusion	Every 2 weeks	24	27.3
	Every 3 weeks	27	30.7
	Every 4 weeks	37	42.0

Table (1) shows the distribution of the socio demographic characteristics of 88 patients undergoing thalassemia major that attend to Jeen pediatric hematology and oncology center in Duhok city. The highest percentage of patients were more than 10 years (45.5%), also the highest percentage of patients were male (60.2%), Also it appears from table (59.1%) of the sample were non student. It is also obvious from the table that (50%) with negative history of thalassemia. With regard to level of income, it appears that majority of the sample (51.1%) were moderate income. With regard to the splenectomy the highest percentage (54.5%) with negative history, the table also shows that the majority of children (42%) take blood every four weeks

Table (2) :Association between children QOL domains and children age

Quality of life	QOL level	Age (Year) 5- year F	10- year F	15- year F	Total	X^2	P. value
Physical	Good	12	27	15	54	1.214	0.05
	Poor	10	13	11	34		
	Total	22	40	26	88		
Emotional	Good	9	23	14	46	1.603	0.04
	Poor	13	17	12	42		
	Total	22	40	26	88		
Social	Good	11	21	10	42	1.305	0.05
	Poor	11	19	16	46		
	Total	22	40	26	88		
School	Good	14	24	11	49	2.751	0.02
	Poor	8	16	15	39		
	Total	22	40	26	88		

Table (2) shows that there was not statistically associations in all domains of QOL among children regard to their ages.

Table (3) :Association between children's QoL domains and gender

Quality of life	QOL level	Gender		Total	X^2	P. value
		Male F (%)	Female F (%)			
Physical	Good	20	17	37	1.016	0.03
	Poor	33	18	51		
	Total	53	35	88		
Emotional	Good	23	20	43	1.594	0.02
	Poor	30	15	45		
	Total	53	35	88		
Social	Good	26	22	48	1.6193	0.02
	Poor	27	13	40		
	Total	53	35	88		
School	Good	25	21	46	1.391	0.02
	Poor	28	14	42		
	Total	53	35	88		

Table (3) shows the quality of life scores were better for males as compared to females but this difference was not significant associations in all domains of QOL.

Table (4) :Association between family history of children and QoL domains.

Quality of life	QOL level	Family history		Total	X^2	P. value
		Positive F (%)	Negative F (%)			
Physical	Good	20	26	46	1.639	0.02
	Poor	24	18	42		
	Total	44	44	88		
Emotional	Good	30	23	53	2.325	0.01
	Poor	14	21	35		
	Total	44	44	88		
Social	Good	28	22	50	1.667	0.02
	Poor	16	22	38		
	Total	44	44	88		
School	Good	24	17	41	2.238	0.01
	Poor	20	27	47		
	Total	44	44	88		

Table (4) shows that there were significant associations in all domains of quality of life with regard to the family history of thalassemia.

Table (5) :Association between the children QoL domains and income level.

Quality of life	QOL level	Income level			Total	X^2	P. value
		Low F (%)	Moderate F (%)	High F (%)			
Physical	Good	12	29	9	50	11.182	0.003
	Poor	21	16	1	38		
	Total	33	45	10	88		
Emotional	Good	12	33	3	48	13.237	0.001
	Poor	21	12	7	40		
	Total	33	45	10	88		
Social	Good	15	36	4	55	12.131	0.002
	Poor	18	9	6	33		
	Total	33	45	10	88		
School	Good	16	35	2	53	14.442	0.007
	Poor	17	10	8	35		
	Total	33	45	10	88		

Table (5): shows that there were significant associations in domains of quality of life with regard to level of income.

Table (6): Association between children's QOL domains and history of splenectomy.

Quality of life	QOL level	History of splenectomy		Total	X^2	P.vlaue
		Positive F (%)	Negative F (%)			
Physical	Good	17	39	56	14.158	0.008
	Poor	23	9	32		
	Total	40	48	88		
Emotional	Good	13	29	42	13.132	0.009
	Poor	27	19	46		
	Total	40	48	88		
Social	Good	15	33	48	12.119	0.01
	Poor	25	19	44		
	Total	40	48	88		
School	Good	28	36	64	16.517	0.05
	Poor	12	12	24		
	Total	40	48	88		

Table (6): demonstrates that there were significant associations in all domains of quality of life with regard to history of splenectomy.

Table (7):Association between Frequency of blood transfusion and QoL domains.

Quality of life	QOL level	Frequency of blood transfusion Every 2 weeks F (%)	Every 3 weeks F (%)	Every 4 weeks F (%)	Total	X^2	P. value
Physical	Good	7	7	24	38	12.29	0.002
	Poor	17	20	13	50		
	Total	24	27	37	88		
Emotional	Good	19	7	15	41	15.41	0.004
	Poor	5	20	22	47		
	Total	24	27	37	88		
Social	Good	17	6	20	43	12.7	0.001
	Poor	7	21	17	45		
	Total	24	27	37	88		
School	Good	18	8	24	50	12.34	0.002
	Poor	6	19	13	38		
	Total	24	27	37	88		

Table (7) shows that there were significant associations in domains of quality of life with regard to frequency of blood transfusion.

Discussion:

Thalassemia Major has turn into a major overall health problem during the world, particularly in poor and developing countries **(15).**

In order to know whether there are effects of the sociodemographic characteristics of patients on the score of quality of life, the researcher categorized the sample of the study to many groups according to certain variables (Age, gender, education, family history of thalassemia, income level, history of splenectomy, and frequency of blood transfusion).

Figure (1) demonstrate (59.1 %) of the patients were educationally retarded. Frequent visits to health centers for blood transfusion may lead to absenteeism from work and school. Study of Khani et al. shows that 36.7% of the participants were educationally retarded in Mazandaran province-Iran **(16)**. Pakbaz Z, Treadwell M (2005) and Ayoub MD, Radi SA,(2013) They shows in their studies that thalassemia patients dealt with great deficiencies in terms of academic achievement which was due to absenteeism from school for the purpose of visiting health centers and practitioners for blood transfusion. **(17, 18)**

The study revealed that there was no significant statistical association between all domains of QOL among children regard to their ages.This result supported by Tahmasbi S, Ayyen F, Heravikrymvyy M. **(19)** study which indicate that there were no significant correlation was found between patients' age and quality of life. However, in a study by Thavorncharoensap et al(17) the correlation between age and quality of life was found significant (P value<0.05).table (2).

Table (3) shows that the total quality of life scores were better in males as compared to females but this difference was not statistically significant associations in domains of QOL regard to the gender of children. The lower scores in females may be due to poor attention given to female's child in our community. Support for this finding was reported by (Thavorncharoensap M, Torcharus K,. 2010, Gharaibeh HF, Gharaibeh MK 2012)**(20,21)**who indicated that females had significantly lower scores of quality of

life and other study have shown difference between males and females (Caocci G, Efficace F. 2015)[22]

Table (4) indicates that quality of life had non-significant relationship regard to the familyhistory. This result is disagreement with (Shahram Baraz1. et al,)[23] which indicates that there are significant correlation between family history and low scores of quality of life.

With regard to the level of income, patients whose families had low incomes per month had a significantly lower scores compared with those whose families who had high income per month and there were significant differences in all scores of quality of life (table 5).This result is an agreement with the results of (Abdulrahman. Et al,)[24]which indicate that there were significant differences between all scores of quality of life with regard to the income level.

According to history of splenectomy, it was revealed that there were significant associations between all domains of quality of life (table 6), as in the study by Tahmasebi et al.[3]In Dahlui et al [25]study, correlation between splenectomy and quality of life was insignificant (P-value= 0.058).

It appears from table (7) the negative effect of total numbers of visits per month and frequencies of blood transfusion on total quality of life scores in our study children with one time blood transfusion per month had best total QoL scores as compared to children visiting three times per month for blood transfusion. This result was similar to that reported by Surapolchai et al.[26] while Hadi et al.[27]reported a negative correlation between quality of life and frequency of blood transfusion.

Conclusion:

According to the objectives of the present study and the results of the data analysis, the following conclusion was been inferred:

There are tangible problems in all (physical, psychological, social and environmental) domains whereas the physical domain comes first in rank.

There were poor statistically significant association between the all domains of Q.o.L and some variables like (age, and gender).

There were strong statistically significant association between the all domains of Q.o.L and some variables like (education level, Family history, income level, History of splenectomy, and Frequency of blood transfusion).

Recommendations:

1. The authorities should develop plans to improve quality of life of these patients.
2. Early diagnosis, regular visiting, financial and education support are the major factors of intervention to improve the overall quality of life of these children.
3. The researcher also recommends conducting further studies on large samples.

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