Assess Quality of Life of Children with Beta Thalassemia Major

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ABSTRACT

Background: It is imperative to know further about QOL in children to assess and improve the care that they receive. Quality of life varies from other forms of medical assessments in that it emphases on the people's own opinions of their welfare and other features of life. ***Aim of study*:** Assess the quality of life among children with beta-thalassemia. ***Design:*** A descriptive research design was utilized in this study. ***Setting****:* the study was carried out at the outpatient hematology clinic at Mansoura University children's hospital in Dakahlia governorate. ***Sample***: the study sample was collected from 124 children with beta thalassemia major. ***Results:*** Almost all the studied children who complied with blood transfusion had low QOL. Also, the majority compliant with chelation therapy had low QOL. The studied thalassemic children experienced moderate QOL related to physical, emotional, and school functioning and experienced high QOL regarding social functioning. ***Conclusion:*** the highest percentage of the studied children had moderate levels of QOL. There was a statistically significant association between children's QOL and their knowledge. Moreover, there was a positive relation between children's ages and their total scores of QOL. ***Recommendation:*** regular and continuous health education programs are essential for children suffering from beta thalassemia and their mothers.

Key words: Quality of life; beta thalassemia major children.

INTRODUCTION

Thalassemia is the most common hemoglobin disorder in the world. It is an inherited disease, where if the parents are carriers or affected, their children will have high probability of being affected too. Different types of thalassemia lead to diverse disorders in patients. The most severe form of thalassemia, beta-thalassemia major, will most likely cause death. Thalassemia is a severe public health problem in the Mediterranean area, in addition to has no cure ***(Alam, 2009; Safizadeh et al., 2012; Raza et al., 2015)***.

Thalassemia is a major health problem in Egypt where 1–5 million neonates are anticipated to be affected with this illness, and it is the greatest common chronic hemolytic anemia (85.1%). A high rate of carriers has been reported in Egypt ranging from 4–5% reaching up to 9–10% ***(Shawky et al., 2011; Shanshory et al., 2014)***. Thalassemia has an effect on the formation of the globine chain. Signs symptoms may vary depending on the number and type of chains involved ***(Sabry et al., 2009; Safizadeh et al., 2012).***

There are physiological changes in the body structures of children with severe diseases related to hemochromatosis such as growth retardation and delayed or absent sexual maturation in many adolescents. Moreover, most children treated with blood transfusion and early chelation therapy survives well into adulthood. The most common causes of death are heart diseases, post-splenectomy sepsis, and multi organ failure secondary to hemochromatosis ***(Wilson et al., 2011)***. The treatment strategies of beta-thalassemia major emphasis on just how to treat its manifestations and chronic complications using the best current treatment approaches for beta-thalassemia, transfusion therapy, oral iron chelation therapy, splenectomy, endocrinopathies, cardiac complications, in addition to hematopoietic stem cell transplantation ***(Eliezer et al., 2016)***.

The transfusion requirements increase with time and children develop iron overload for which children require chelation ***(Naggarwal et al., 2011).*** Thalassemia has no cure, so the goal of treatment is to normalize the hemoglobin and hematocrit of the child, thus alleviating the symptoms of severe anemia. This

is accomplished via a regular schedule of transfusions, with many children requiring transfusions every 2 to 3 weeks ***(Potts et al., 2012).***

Thalassemic children and adolescents, in comparison with children who would have short-term injuries, have more depressive symptoms and lower quality of life (QOL). Also, anxiety, depression, aggression and shyness are higher in thalassemic children than healthy ones. Moreover, anxiety and depression were in 47% of the children, this brought about problems in their self-care and QOL ***(Borhani et al., 2011)***. Thalassemia not only affects the child's physical performance but also the school achievement, emotional in addition to social aspects ***(Thavorncharoensap et al., 2010; Kahouei et al., 2016).***

The nurse has a great and important role in management of children with thalassemia. The nurse plans and carries out the goals of nursing management, and teaches and supports children and their families about thalassemia to improve the children's QOL. Moreover, the nurse assists in genetic counseling that leads to marked decline in the number of new cases of thalassemia worldwide ***(Wilson et al., 2011)***.

Significant of the study:

Children with chronic disease, demonstrated thalassemia, are prone to emotional and behavioral problems which are reasons of poor quality of their lives ***(El–Dakahkny, 2011; Ayoub et al., 2013; Nasiri et al., 2013).*** Quality of life studies could be used to supply information about the disease progression and its impaction children's life . So, there is a need to study the quality of life for thalassemia children.

AIM OF THE STUDY

The current study aimed to assess the quality of life among children with beta-thalassemia.

Research question

What is quality of life among children with beta-thalassemia?

SUBJECTS AND METHOD:-

Research Design:

For proceeding of this study, the descriptive research design was used

Study Setting

Current study carried out at the outpatient hematology clinic at Mansoura University children's hospital in Dakahlia governorate.

Study Subjects:

Convenience sampling of 124 children with beta-thalassemia major was the following criteria:

1. Age between 6-18 years.
2. Both sexes.
3. Free from any other chronic disease except complication of beta thalassemia

The process of data collection took a period of nearly two months from 1/2015 to 2/2015.

Data collection tools:

The present study used the following tools:

TOOL (I): Arranged Interview schedule Sheet*:*

This tool was developing by the researcher. It included two parts:

Part I: children demographic characteristics and his parents as, their age, rank, gender and educational level. Patient characteristics as age, educational level, occupation, family size and income.

Part II: Medical history about disease history, onset of manifestations, any similar conditions in the family, child's age at diagnosis of thalassemia.

Part II: Knowledge of children and their mother about thalassemia disease as; definition, nutrition, activities, frequency of blood transfusions each month, complying of blood transfusion and chelation treatment.

Children knowledge will be scored as following:

- Correct and complete answer will be scored (2)
- Correct and incomplete answer will be scored (1)
- Wrong answer or don't know and will be scored (0)

The total score of children knowledge will be calculated and classified into three levels as following:

- 60% will be considered poor knowledge.
- 60- 75% will be considered fair knowledge.
- 75-100 % will be considered good knowledge.

TOOL (II): The Pediatric Quality of Life Inventory Version 4.0 by *Varni et al., (1998 (Appendix II):*

PedsQL; is a modular methodology to assess health- related quality of life (HRQOL) in kids and teen-agers with acute in addition to chronic health conditions. The PedsQL was used to measure the QOL for children with beta thalassemia major. This form assessed: Young children's QOL (ages 6-7), Children's QOL (ages 8-12) and adolescents' QOL (ages 13-18).

Scoring system

Scoring of studied thalassemic children's knowledge and their mothers:

For each question, right answer recorded (1) while wrong response was scored (0). For each area of knowledge, the scores of the items were summed and the whole score split-up by the number of the items, providing a mean score for the part. These scores were turn into percentage, means and standard deviations were calculated. Knowledge was reflected satisfactory if the percentage was 50% or more, and unsatisfactory if < 50%.

Quality of Life (QOL) Scoring System *(Varni et al., 1998)*:

The PedsQL 4.0 generic core inventory subscales were involved of children reports that comprised ages; (6 to 7) years, (8 to 12) years, and (13 to 18) years (adolescence).

5- Likert scale: 0 for never to 4 for (almost always) for ages 8-12 years and 13- 18 years.

3- Likert scale: 0 for never, 2 (sometimes) and 4 (always) for the young children aged 6-7 years.

Items were reverse–scored and linearly distorted to a 0-100 scale as follows:

Items **Score**

- Never: 100
- Almost never: 75
- Sometimes: 50
- Often: 25
- Almost always: 0

The scores were transform into a percentage, the QOL was shown "high" if percentage was 60% or more; "moderate" when percentage ranged from 30% to less than 60%", and "low" if less than 30%.

(II) OPERATIONAL DESIGN

The operational design included content fieldwork, validity & reliability and pilot study.

Fieldwork:

The process of data collection took a period of nearly two months from 1/2015 to 2/2015. This period consumed for data collection was governed by the availability of time for both the researcher and the study respondents. An official permission was taken. The time consumed to interview the child and his/her parents, the allocated was "20 - 25 minute". The appropriate number of children and accompanying parents per interview was 5. The researcher was available three days each week, this time was determined according to children's times of presence in the hospital.

Validity and Reliability:

Tools were developed and its content validity was confirmed by five pediatric consultants in nursing field. Correlation of reliability for tools constituted a total scale score of 0.88 child self-report and Cronbach’s Alpha.

Pilot Study:

It was accomplished on 10% of studied children (12 child), to check the clearness of questions and estimation of the time needed for completing each sheet. Some modifications were done to the interview questionnaire sheet.

Ethical considerations

Oral consent from children and their parents was obtained for their involvement in the study after explanation the purpose of the study and informing them that all the collected data were confidential and will be used only for the purpose of the study.

Statistically analyzing of the data:

Data were coded and transferred into specially-designed formats for data entry, then data were analyzed and computed using the statistical package for social sciences (SPSS version 16.0), which was used for statistical analysis. The collected data were organized, categorized, tabulated in tables using numbers, percentage, mean percentage and standard deviation. Chi-square test applied to test the relations between studied qualitative variables.

RESULTS:

Figure (1): showed frequency distribution of the study sample "children with thalassemia" regarding to their age, the figure illustrated that more than one third of the studied thalassemic children **(38.7%, and 36.3%)** ranged in age from 6<10, and 10<14 years respectively, while the rest of them **(25%)** were aged from 14≤18 years with the mean age 10.73 ± 3.61.

Figure (2): cleared studied children`s frequency and distribution regarding to their genders, also the figure indicated that more than one half of studied children were females **(52%)**.

Figure (3): illustrating the frequency distribution of the studied thalassemic children according to their educational levels, it indicated that the highest percentage of the studied thalassemic children **(70.2%)** were in primary schools.

Table (1): showed total score QOL dimensions, it indicated that the emotional functioning recorded the lowermost then the following score was physical thereafter social and school tasks. Overall**, 28.2%** of the studied thalassemic children had low levels of total QOL, while **52.4%** had moderate levels.

Table(2): revealed the relationship between studied children`s quality of life and their commitment of blood transfusion, chelation treatment, activities and suitable nutrition, it was found that almost all the studied children **(97.1%)** who complied with blood transfusion had low QOL. Also, the majority **(82.8%)**

compliant with chelation therapy had low QOL. In addition to, statistical significance relation was found between children's quality of life and their adherence to suitable nutrition (P ≤ 0001*).

Table (3): showed the correlation coefficient between children`s quality of life and their age, education, mothers' age and education, and child's knowledge. It revealed that there was a positive relation between child's age and education, and their total score of QOL with statistical significance (P= .000, and .021 respectively). On the other hand, there was a negative correlation between children`s QOL and their knowledge (P= .024).

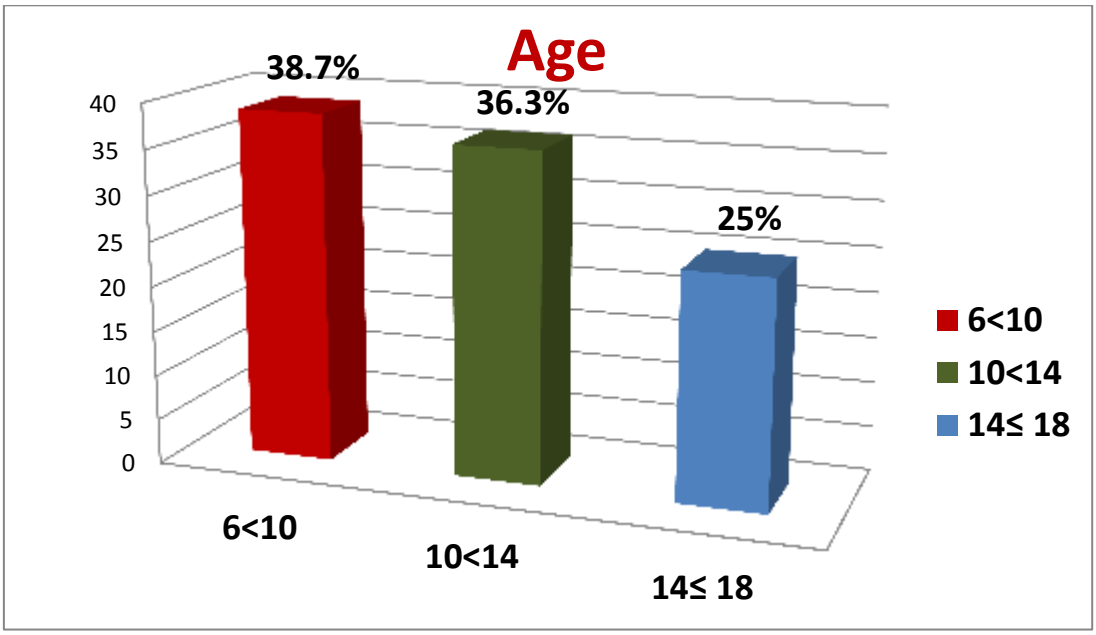

Figure 1: Frequency distribution of the studied thalassemic children according to their age

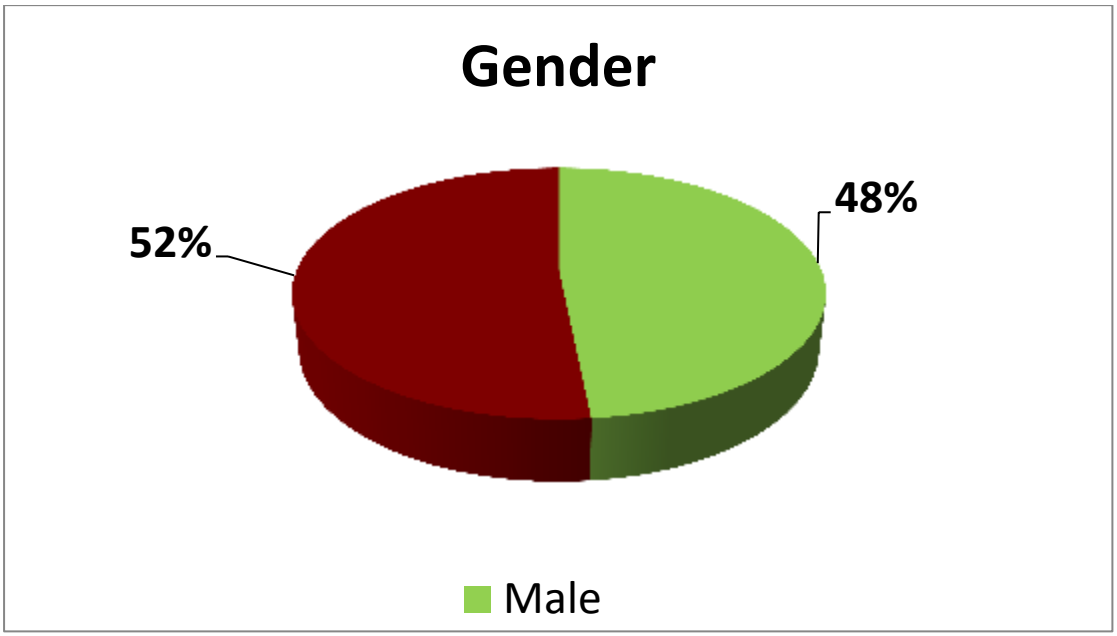

Figure 2: Frequency distribution of children with thalassemia who included in the study regarding to their genders.

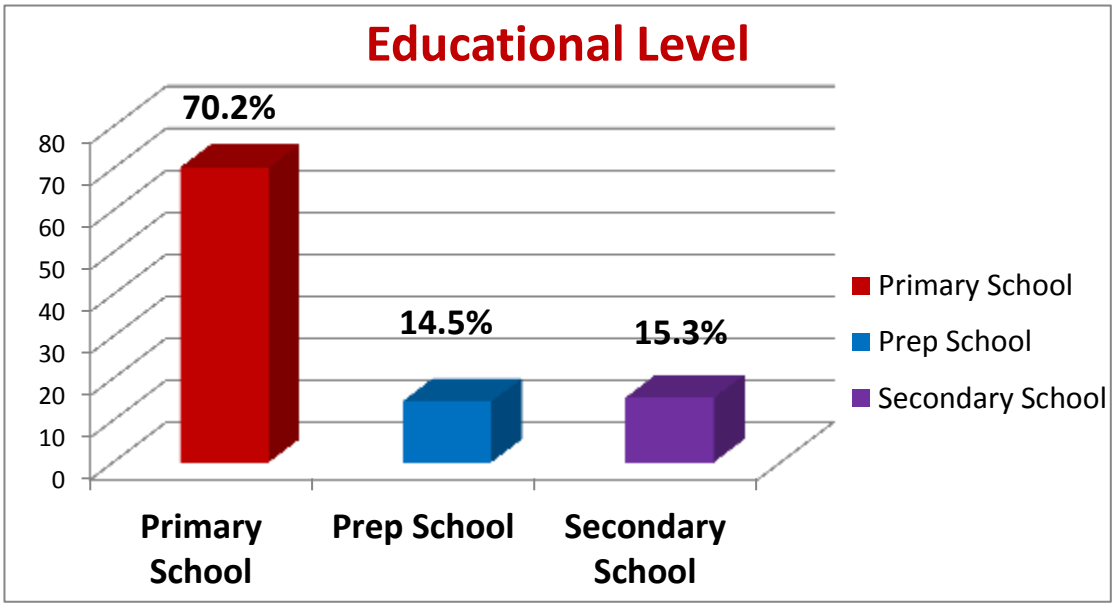

Figure 3: Frequency distribution of the studied thalassemic children according to their educational levels

Table (1): Frequency distribution of QOL dimensions of studied thalassemic children (n= 124).

QOL dimensions:	**Total QOL level**					
	High		**Moderate**		**Low**	
	No.	**%**	**No.**	**%**	**No.**	**%**
Physical.	52	**41.9**	51	41.1	21	16.9
Emotional.	20	16.1	63	**50.8**	41	33.1
Social.	74	**59.6**	25	20.2	25	20.2
School.	12	9.7	93	**75**	19	15.3
Total	24	19.4	65	**52.4**	35	**28.2**

Table (2): Relationship between study sample quality of life and their adherence with blood transfusion, chelation treatment, activities and suitable nutrition (n=124).

Compliance with:	**Total QOL level**						**Total**		X^2	**P-value**
	High		**Moderate**		**Low**					
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**		
Blood transfusion:										
Compliant.	20	83.3	55	84.6	34	**97.1**	109	87.9	3.942	.139
Incompliant.	4	16.7	10	15.4	1	2.9	15	12.1		
Chelation therapy:										
Compliant.	22	91.7	53	81.5	29	**82.8**	104	83.9	1.994	.369
Incompliant.	2	8.3	12	18.5	6	17.1	20	16.1		
Activities:										
Performing daily activities.	24	100	54	83.1	29	82.9	107	86.3	4.729	.094
Not performing.	0	0	11	16.9	6	17.1	17	13.7		
Adherence to suitable nutrition:										
Adhered.	3	12.5	3	4.6	11	31.4	17	13.7	13.863	.001*
Not adhered.	21	87.5	62	95.4	24	68.6	107	86.3		
Total	24	100	65	100	35	100	124	100		

Significant P < .05.

Table (3): Correlation coefficient between children`s quality of life and their age, education and children's knowledge.

	Total child QOL	
	r	**P**
Children's age.	.318**	.000*
Children's education.	.206*	.021*
Children's knowledge.	-.202	.024*

Significant P < .05

DISCUSSION:

Beta-thalassemia is a lifelong illness which has a devastating impact on children ***(Ishfaq, 2016).*** Children with chronic diseases such as thalassemia require self-management of their disease in addition to treatment plans to enhance quality of life (QOL), this may increase compliance, and there by improve children's status ***(Baghianimoghadam et al., 2011)***.

The highest percentage of studied children had moderate and low levels of QOL regarding emotional functioning, but the lowest percentage of them had moderate and low QOL regarding social functioning. The results of the present study were in contrast with ***Baraz et al. (2015),*** who studied comparison of quality of life among youths complaining of beta-thalassemia major and healthy peers**,** reported that the mental health had the lowest mean score, while the mean score was high in social aspects of quality of life in the studied children.

Results of the present study found school functioning score was the highest followed by social then physical and emotional ones. This finding in congruent with ***Elalfy et al. (2014),*** their study cleared school functioning scores were better than the physical domain scores as children attended the clinics for blood transfusions on Saturdays which were the schools' day-off.

It was also observed from the present study that the physical domain had the lowest scores of total QOL. This was expected to have been due to the

consequent complications of beta-thalassemia major like cardiac failure that limited children from making exercises as running and lifting heavy objects. The present study was also congruent with ***Torcharus et al. (2011),*** their study revealed psychological and social wellbeing scored higher than physical and emotional functioning. Moreover, the present study contrasted with ***Mahmoud et al. (2015),*** who found that the studied children had low expectations of physical performance because they have been living with the disease for long time without the burden of work.

Transferring the blood in addition to chelation therapy considered a backbone in the managing of beta-thalassemia major. Initial and steady transferring of the blood declines correlated problems of severe anemia and increase life expectancy ***(Ragab et al., 2013).*** Current study revealed the majority of studied sample who were compliant with blood transfusion had low QOL. This result could be interpreted by the fact that the low hemoglobin level leads to a lot of health problems like tiredness, overall weak, and diminished intellectual awareness ***(Hockenberry et al., 2013).*** Also, there are infections like HCV, HBV, HIV, malaria, syphilis and HTLV that are transmitted to children through blood transfusion which leads to low QOL ***(Naggarwal et al., 2011)***. The results of this study were congruent with ***Thavorncharoensap et al. (2010),*** their study clarified that for those who transfused by blood, there were positive relation which was significantly between children who received blood transfusion and their low health related quality of life, it might be clarified by children who receiving blood through 3 months before the health-related quality of life estimation who had minimum level of hemoglobin before transfusion. Also, ***Baraz et al. (2015),*** revealed the presence of negative relationship between children`s quality of life in addition to the frequency of blood transfusions.

The present study reported that the majority of studied children were adhered with chelation treatment. It might have been because short period of intravenous infusion of desferal. This goes in line with ***Mazzone et al. (2009),*** who observed emotional effect on thalassemia major after psychotherapy for the family in addition to quality of life of caregivers, and found that the majority of the beta-thalassemia major children had good compliance with chelation therapy.

However, current study results were dissimilarity to ***Haghpanah et al. (2013)***, who discovered that children who were strict compliant with chelation treatment had high quality of life score. In addition, ***Goulas et al. (2012),*** mentioned that children receiving chelation therapy had lower self-esteem and worse physical scores.

The present study showed positive relation between children age and their total QOL score. This may have been because the studied children got used to the presence of the chronic disease while their ages advanced. This finding was consistent with ***Dahlui et al. (2009),*** who clarified this finding due to the children being able to value health more and realize the limitations of their roles due to the disease as their ages advanced. Similar to ***Gupta et al. (2013),*** who mentioned that age significantly influenced the QOL, these results were congruent with ***Thavorncharoensap et al. (2010),*** their study revealed that teenager children`s health related QOL score was higher than the youngest ones.

The present study results were in contrast with ***Amani et al. (2015),*** who clarified that there wasn't significantly correlation between children's age and the quality of life scores. The current study reported positive relation between children's education and their QOL score. This may have been due to that education helps thalassemia children have suitable academic performance that makes them depend on themselves and socially live without problems. This result goes in line with ***Ansari et al. (2014)***, who mentioned that education had effect on numerous components quality of life.

CONCLUSION:

The highest percentage of the studied children had moderate levels of QOL. There was a statistically significance relation between studied children QOL and their knowledge. Moreover, positive correlation between children ages and their total QOL score.

RECOMMENDATIONS:

Health educational programs about thalassemia disease and nursing care are essential for children with beta thalassemia and their mothers.

Beta thalassemia major education should be maintained through a multidisciplinary approach over a prolonged outpatient, inpatient, and community education service plan for beta thalassemia children and their mothers.

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الـــخـــلاصـــة

توفير الرعاية الأمثل عنصر حيوى فى تحسين جودة حياة الاطفال المصابين بأنيميا البحر المتوسط (الثلاسيميا)، فقد تقدمت للأحسن بالمواظبة على نقل الدم والتخلص من نسبة الحديد الزائدة الناتجة عن تكرار نقل الدم. ولذلك أجريت هذه الدراسة بهدف تقييم جودة حياة الاطفال المصابين بأنيميا البحر المتوسط (الثلاسيميا)، حيث أجريت هذة الدراسة على 124 طفل مصاب بأنيميا البحر المتوسط (الثلاسيميا) فى رفقة ذويهم فى عيادة أمراض الدم فى مستشفى الأطفال الجامعى فى المنصورة بمحافظة الدقهلية. تم جمع البيانات باستخدام اداتين، الأولى تشمل معلومات عن الطفل المصاب بأنيميا البحر المتوسط (الثلاسيميا)، والثانية عن جودة الحياة للأطفال (الاصدار الرابع). وقد أسفرت نتائج الدراسة أن جودة حياة الأطفال المصابين بأنيميا البحر المتوسط (الثلاسيميا) كانت متوسطة بمقدار 41.1٪، 50.8٪، 75.0٪ للوظيفة البدنية والعاطفية والمدرسية على التوالى. بينما حققت الحياة الاجتماعية جودة حياة عالية بمقدار 59.6٪. علاوة على ذلك، كانت هناك علاقة ذات دلالة احصائية بين جودة حياة الاطفال ومعلوماتهم (P = ,*024). وأوصت هذه الدراسة بضرورة وجود المزيد من البرامج التعليمية الصحية المنظمة والمستمرة التى تقدم المعلومات والإرشادات عن مرض أنيميا البحر المتوسط (الثلاسيميا) للأطفال المصابة بهذا المرض وذويهم.

الكلمات المرشدة : جودة الحياة ، أطفال مصابة بأنيميا البحر المتوسط .