ASSESSMENT OF HEALTH QUALITY OF LIFE UPON SCHOOL AGE CHILDREN (6 – 12) WITH THALASSEMIA AT THALASSEMIA CENTRE IN IBN- BALADI HOSPITAL.

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ABSTRACT

Objectives: assess the QOL of thalassemia school age children and relation ship with some variables.

Methodology: Non- probability (purposive) sample of (40) patient school age children with thalassemia hospitalized for management were selected .The questionnaire format designed for the purpose of the study, two instrument were used include : sample demographic characteristics QOL domain of thalassemia school children . Data were analyzed by using frequencies, percentage. and multi-regression analysis

Results: The result of the study indicated that the majority of the sample was the age group (9-11) and (6-8) and 75% of the subject of the study have (1-2) affected brothers .

Regarding the age of onset shows that the majority of thalassemia have the disease between the (6-10) month of there life ,57.5% of the patient suffer from thalassemia major and 67.5% had family history. Over half (72.5%) of patient feel tired when he or she gait due to sign and symptom of there disease , majority of the sample 87.5% depended on blood transfusion and 85% of thalassemia patient need to desferal. While the majority of the patient 85% feel bad because can't do what their friend doing and 70% of patient felt comfort from other supported (nurse, doctor) emotional and psychologically in the center and provide what they need.

Recommendation: The study recommend further studies should consider more generic measure of psychological and social functioning related QOL. In addition need for Educational program for those patients should be designed to help them live a better life with hemophilia disease , the patients emphasize the importance of how to cope with their problems for a good QOL.

INTRODUCTION

The impact of chronic illness is major burden on both the individual patient and society .it may affect the quality of life and impair schooling and work (1) thalassemiae is one of chronic illness this term derived was first described by Cooley and Lee in 1952 in several Italian children as a severe anemia with spleen and liver enlargement, skin discoloration, and bony changes(2) . (3) Stated that management of patient with thalassemia is based on adequate safe blood transfusion and iron – chelating agent used in innovative way to improve the QOL and improve survival of patient with beta – thalassemia. Thalassemia as disease (sign and symptom, complication ,treatment affect on the daily activity of patient and affect on the QOL.

METHODOLOGY

Design of the Study:

descriptive study design was conducted on (school age) having thalassemia, in order to assess the quality of life of thalassemia school children

Administrative arrangement:

The administrative permission were obtained from the thalassemia center in (IBN – BALADI HOSPITAL)

Setting of the study

the present study was carried out in thalassemia center in (IBN – BALADI) hospital

The Sample of the Study:

Non – probability (purposive) sample of (40) school age with diagnosed hospitalized for management .

Instrument of the study:

A questionnaire was It is composed of two parts:

Part I: Demographic Characteristic

It was consisted of (**5)** items which included: demographical data of the sample (Age , level of education , total number of brother and sister , number of affected brother and affected . sister), (3) items related disease information include (age at onset , severity of disease history of the disease) .

Part II: quality of life questionnaire the

quality of life questionnaire the comprised of structured (41) items concerning 4 domains (domains . (appendix B)

these domains are

1- Physical domain (10 items)
2- Independent domain (12 items)
3- Psychological domain (10 items)
4- Social relationship (9 items)

RESULT

Table (1) A + B ; - shows that the highest percentage (42. 5 % , 35 %) of thalassemia school age group (9 – 11) and (6 – 8) respectively , (70 %) graduated from primary school , (37 . 5 %) have (1 – 3) brother and sister , 75 % , have affected brothers . while (52 – 5 %) have affected sister .

Table (1) (B) show that the highest percentage (40 %) of the sample their age at onset were (6 – 10) months the majority (57 . 5 %) of thalassemia patient are suffering from major thalssemia regarding to the family history

(67 .5) of the sample have history of thalassemia .

Table (2) shows that the majority of the sample (70 %) feel pain when diriment any think and (75 – 5 %) feel tired when he she gait become feel in thalassemia . taint and (67.5 %) of the sample felt pain when movement or felt loss off weight more than half (87 . 5 % of the patient dependent on blood transfusion and (85 %) 0f the sample need to desferal as treatment and the masonry of the sample (71 . 5) of patient say the blood transfusion say my life) . (72.5 %) of the patient felt difficult to do the hobbies (bicycle ride , football playing) . (85 % of the sampling feel bad became he or she can't do what the peers doing and No chance to competence with he or she friends more than half (70 %) of sample felt thathe or she is suporrted , emotional and psychological from (Nurse , doctor) .

The table(3) shows a highly significant association between thalassic school age characteristic and all quality of life domain except Affected brother number ,which has no significant association with (QOL domains). Age and Educational level has no significant association with (Independent) while the significant association with (Physical, Psychological, Social).

The table (4) shows a highly significant association between disease information of **thalassemia school age children** and all quality of life domain except Affected age ,which has no significant association with (Psychological, social). while the disease severity has no significant association(physical ,Independend,). .At last the Family history has significant association with with all quality of life domain.

DISCUSSION:-

The majority of the sample was at age group (9-11) and (6-8) they were suffer of the disease ,During this period the peers become influences rather than the parent they don't like to take any advice from their parents concerning their disease. The height percentage of those patient graduated from primary school and more of them absence from the school and interrupt educational process and limit their activity. Concerning affected brothers most of subjects of the study have (1-2) affected brothers and represent 75% while (52.5%) have affected sister, This result indicated that more than one in the family are suffering from the same disease which may reduce suffering .Regarding the age of onset of thalassemia disease in table 1(b)) shows that the majority of thalassemia have the disease between (6-9) month of their life, (4) indicated that features of thalassemia usually develop after 6 month of age when hemoglobin synthesis switches from hemoglobin F (Fetus) to hemoglobin A (Adult).A high percentage (57.5%) of the patient suffer from thalassemia major, (4) mentioned that the severe form of the illness associated with homozygous state , in this condition ,thalassemia genes are inherited from both parents. In relation to the family history of the disease the majority of the sample (67.5%) had a family history .this percentages consider that he thalassemia disease as an inherited disease. Table (2) shows that the majority of the sample (70%) feel pain when doing any thing during their life, Beta thalassmla is associated with bone abnormalities characterized by bone marrow expansion and osteopenia (5). More than half (72.5%)of patient feel tired when he or she gait due to sign and symptom of the disease especially accumulation of the iron . A person with major thalasemia may have anemia pale or jaundice poor appetite ,restricted development ad irritability fail to grow normally (6).There fore we can see (67.5%) of patient feel loss of weight and heavy movement cause pain in the joint that represent 60% of the sample. For all the previous cause the patient thing a lot when he or she go to picnics ad represented 65% . (7) Saied school age children are developing confident in their abilities to control their feeling and action ,hospitalization places them in the position of feeling out of control because it interrupts their routine and their independent feeling of control which increase the stress. About (85%)of the thalassemia patient needs to desfarel that need to reduce the iron over load in their body and majority of the sample (87.5%) depend on blood transfusion

(8) said that blood transfusion and (chelation theropy) that called deferriox required to treat sew thalassemia they removed mostly by the drug. Majority of the patient 85% feel bad because cant do what their friend doing and this impact on their life ad felt have no power to do what their friend are a capable of doing.Between (6-12)age children prefer friend of their owns sex and usually would rather be in the company of their friend than of their friend than of their brothers and sister

(9).The majority of patient 70% felt comfort from other supported(nurse, doctor) emotional and psychologically in the centre and provided what they need .and (67.5%) of patient stated that their family supported and giving care while the (62.5%) of the patient disturb when their parent continuity of care of them and stated that they have no chance to playing or going alone with their friends. There is a significant association between some of the general information and disease information like : age ,educational level, affected age, and family history and physical domain (Table 3) and (Table 4). thalassemia as a disease lead to the school absence of a large number of thalassemia school age children and limited the activities of one third of them. This indicated also that thalassemia as a disease was a significant impact on the educational status. These results indicated that the patient with major thalassemia may have a problem with QOL rather than the patients with mild disease who should be encouraged to live a normal life .(table 4) shows that the independent domain significantly associated with the affected age and family history while the psychological and social domain has significant association with age, educational level ,disease severity and family history (10) stated that patient with chronic disease such as thalassemia school-loss day are reported by students from 5-17 years who have missed more than half a day of the school in which they are currently enrolled.

RECOMMENDATION

1- Educational program for those patients should be designed to help them live a better life with hemophilia disease , the patients emphasize the importance of how to cope with their problems for a good QOL

2- further studies should consider more generic measure of psychological and social functioning related QOL.

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4- further studies should consider more generic measure of psychological and social functioning related QOL.

TABLES

Table (1): (A) Distribution of the sample according to their socio-demographical data.

Variables	Frequency	%
1- Age		
- 6 – 8 yrs	14	35
- 9 – 11 yrs	17	42.5
- 12 – 14 yrs	9	22.5
Total	**40**	**100%**
2- School achievement		
- primary school	28	70
- intermediate	12	30
Total	**40**	**100%**
3- Brothers and sister number		
- non	1	2.5
-1-3	15	37. 5
- 4 – 6	18	45
- 7 – 9	5	12.5
- 10 – 12	1	2. 5
Total	**40**	**100%**
4- Affected brother		
- non	9	22. 5
- 1 – 2	30	75 %
- 3 – 4	1	2.5
Total	**40**	**100%**
5- Affected sister		
- non	21	52.5
- 1 – 2	16	40
- 3 – 4	3	7.5
Total	**40**	**100%**

Table (1):(B) disease information of school age with thalassemia

Variables	Frequency	%
1-Age at onset of thalassemia (month)		
- 1 – 5 yrs	1	2.5
- 6 – 10 yrs	16	40
- 11 – 15 yrs	8	20
- 16 – 20 yrs	8	20
- 21 – 25 yrs	7	17.5
- 25 – 28 yrs		
Total	**40**	**100%**
2-Disease severity		
- minor	7	17.5
- intermediate	10	25
- major	23	57.5
Total	**40**	**100%**
3-Family history of thalassemia		
- yes	27	67.5
- No	13	32.5
Total	**40**	**100%**

Table (2): thalassemia school quality of life domain with 3 – level scale by total frequencies , percentage

#	The Scale Domain Item	Agree		Uncertain		Disagree	
		F	%	F	%	F	%
	I. Physical Domain						
1	I feel pain when I do any thing	28	70	5	12.5	7	17.5
2	I feel tired when I gait	29	72.5	7	17.5	10	10
3	movement cause pain	27	67.5	8	20	5	12.5
4	I feel pain in my joint	24	60	6	15	10	25
5	my sleep decreased	17	42.5	10	25	13	32.5
6	I feel discomfort when I thought my life in danger	22	55	8	20	10	25
7	I think a lot . when I got picnics	26	65	6	15	8	20
8	I feel general weakness	24	60	9	22.5	7	17.5
9	I feel loss of weight	27	67.5	6	15	7	17.5
10	I feel my body is not beautiful	24	60	6	15	10	25
	2-Independent Domain						
11	**I** felt I need some one to do my work	29	72.5	3	7.5	8	20
12	I depended totally on desfaral	34	85	3	7.5	3	7.5
13	I dependent on blood transfusion	35	87.5	3	7.5	2	5

14	blood transfusion is my life	31	77.5	3	7.5	6	15
15	I'm depended on others to take care of me	24	60	6	15	10	25
16	diffident to continue in school time	28	70	3	7.5	9	22,5
17	frequent absent because of my disease	21	52,5	6	15	13	32,5
18	difficult to share with school activity	20	50	10	25	10	25
19	my disease make me physically handicapped	17	42,5	9	22,5	14	35
20	disease affected my exercise	20	50	11	27,5	9	22,5
21	I suffer a lot to interaet with my disease	24	60	9	22,5	7	17,5
22	difficult to do my hobbies	29	72,5	5	12,5	6	15
	III. Psychological Domain						
23	I feel bad I can't do what my friend do	34	85	2	5	4	10
24	I feel bad for my life	24	60	9	22,5	7	17,5
25	I feel less affected on others	17	42,5	9	22,5	14	35
26	the others saw ma as kindly	22	55	5	12,5	13	32,5
27	my disease decrease relationship with friend	19	47,5	6	15	15	37,5
28	I feel difficulty to making friends	17	42,5	4	10	19	47,5
29	I feel lose my role in my family	14	35	7	17,5	19	47,5
30	I feel tense and disturbed	21	52,5	6	15	13	32,5
31	I blame for my parents	14	35	5	12,5	21	52,5
32	I feel alones	14	35	6	15	20	50
	IV. Social Relationship						
33	I have less relationship with my friends	21	52,5	5	12,5	14	35
34	I like to stay at home	18	45	4	10	18	45
35	My relationship just with my family	20	50	7	17,5	13	32,5
36	Less relationship with my family	12	30	8	20	20	50
37	I disturb when I far way from my friend	15	37,5	10	25	15	37,5
38	I have support from my friend	18	45	9	22,5	13	32,5
39	My family respect me and care about me	27	67,5	3	7,5	10	25
40	Other support me emotionally and psychologically (nurse, doctor)	28	70	2	5	10	25
41	I disturb continuity of care of my family	25	62,5	2	5	13	32,5

Table3: Multiple regression of QOL with thalassic school age characteristic

Domains	Age			Educational. level			Affected brother number		
	β	t	Sig.	β	t	Sig.	B	t	Sig.
Physical	8.500	3.554	**.001**	1.527	2.808	**.009**	-1.241	-1.348	.188
Independent	3.037	1.076	.292	1.150	1.522	.140	1.567	.779	.447
Psychological	8.117	4.558	**.000**	2.210	6.172	**.000**	-9.83	-.135	.894
Social	8.157	7.426	**.000**	2.126	8.691	**.000**	-.209	-.380	.707

Level of significant at P value < 0.05

Table(4): Multiple regression of QOL with disease information of thalassemia school age children

Domains	Affected age (month)			Disease severity			Family history		
	β	t	Sig.	β	t	Sig.	β	t	Sig.
Physical	48.790	3.653	**.001**	1.257	1.616	.117	2.618	5.197	**.000**
Independent	61.374	2.860	**.010**	.444	.357	.724	2.295	2.755	**.011**
Psychological	7.544	.633	.532	2.163	3.600	**.001**	2.002	5.365	**.000**
Social	7.717	.838	.409	1.343	2.976	**.006**	2.025	6.521	**.000**

Level of significant at P value < 0.05

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تقييم نوعية حياة المرضى المصابين بالثلاسيميا في عمر المدرسة (٦-١٢) سنة وعلاقتها ببعض المتغيرات في مركز الثلاسيميا في مستشفى ابن بلدي

د. ختام مطشر الموسوي

الخلاصة

الهدف:

تقييم نوعية حياة المرضى المصابين بالثلاسيميا في عمر المدرسة وعلاقتها ببعض المتغيرات .

المنهجية:

شملت عينة الدراسة (٤٠) مريض يتروح اعمارهم (٦-١٢) مصابين بمرض الثلاسيميا الذين ادخلوا الى المستشفى لغرض العلاج.

تم تعميم الاستمارة الاستبيانية لاغراض الدراسة والمولفة من جزاين (المعلومات العامة للعينة والمعللومات الخاصة بمجالات نوعية الحياة للمرضى المصابين بمرض الثلاسيميا من هم بعمر المدرسة) تم تحليل المعلومات احصائيا باستخدام النسبة المئوية و التكرارات وكذلك الانحار المتعدد الخطي

النتائج:

اظهر تحليل النتائج بان معظم افراد العينة تتروح اعمارهم بين (٩-١١) (٦-٨) وان ٧٥% من العينة لديهم (١-٢) من الاخوان المصابين بنفس المرض . بالنسبة الى العمر عند الاصابة اظهرت النتائج ان معظم مرضى الثلاسيميا تم اصابتهم بالمرض في عمر (٦-١٠) شهر من حياته.و ٧٥% من المرضى مصابون بالنوع الشديد و ٦٧,٥ % لديهم تاريخ مرضي عائلي. اكثر من نصف العينة والتي تشغل نسبة ٧٢,٥% من المرضى يشعرون بالتعب عند المشي وخاصة لمسافات طويلة. ومعظم العينة (٨٧,٥) يعتمدون على على عملية نفل الدم وعلاج اليسفرال . بينما ٨٥% من العينة يشعرون بالسوء لانهم لا يستطيعون عمل الاشياء التي يقوم بها اقرانهم ٧٠% من المرضى ويشعرون بالارتياح من معاملة الفريق الطبي والصحي في المركز .

التوصيات :

توصي الدراسة الى الدراسات المكثفة فيما يخص الجانب الاجتماعي النفسي في نوعية الحيام لمرضى الثلاسيميا بالاضافة الى العناية المكثفة من قبل الفريق الصحي والتنسيق مع وزارة الصحة لاقامة الدورات التدريبية لكادر الصحي والطبي حول مرض الثلاسيما وكيفية العناية بالمرضى.