Determination of Quality of Life for Thalassemic Adolescent

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الخلاصة

خلفية البحث: يعد مرض الثلاسيميا الكبرى من الإمراض الوراثية المنتشرة في منطقة البحر الأبيض المتوسط ولذلك فان تقيم نوعية الحياة خصوصا لأولئك الذين يعانون من الحالات المزمنة مثل الثلاسيميا يكون مهما بشكل واضح.

اهداف الدراسة: تحديد نوعية حياة المراهقين الذين يعانون من الثلاسيميا في مركز فقر دم البحر الأبيض المتوسط في محافظة النجف من خلال الجانب المدرسي .

المنهجية: أجريت دراسة كمية وصفية في مستشفى الزهراء التعليمي مركز الثلاسميا للمدة من 1 تشرين الثاني 2011 ولغاية 15 تموز 2012 لتقيم نوعية حياة المراهقين الذين يعانون من فقر دم البحر الأبيض المتوسط. وإيجاد العلاقة بين جوانب نوعية حياة هؤلاء المرضى والصفات الديموغرافيه الاجتماعية والتاريخ الطبي لهم.اختيرت عينة غير احتمالية "غرضيه " من (70) مريض مصاب بفقر دم البحر الأبيض المتوسط الأكبر الذين يراجعون مركز الثلاسميا في مستشفى الزهراء التعليمي،جمعت المعلومات من خلال استخدام استبانة مصممة ومكونة من ثلاثة أجزاء ، جزء شمل الصفات الديموغرافيه الاجتماعية ويحتوي (4) فقرات وجزء شمل الصفات السريرية والمضاعفات المكون من (5) فقرات.

الاستنتاجات: استنتجت الدراسة إن مرض الثلاسميا شائع الحدوث عند الأشخاص المقيمين في المناطق الحضرية عن اولائك من سكنة المناطق الريفية . ومرض الثلاسميا غالبا ما يحدث عند الرجال أكثر من النساء.ايضا اكدت الدراسة على ان مرض الثلاسيميا يوثر بشكل كبير على المستوى التعليمي للإفراد. كما اظهرت الدراسة انخفاض التقييم العام لنوعية حياة المرضى.

التوصيات توفير أخصائي نفسي في وحدات الدم و العيادات الخارجية على أن يكون حلقة وصل بين المرضى ومسؤولي المدارس، والأسر، والأطباء. وينبغي أن وسائل الإعلام لها دور في توفير المعلومات للسكان حول مرض الثلاسيميا وغيرها من الأمراض الوراثية

Abstract

Background: Thalassemia major is a prevalent hereditary disease in Mediterranean region, so that the assessment of quality of life, especially in those with chronic illnesses such as thalassemia is particularly important.

Objectives : To assess thalassemic adolescents′ quality of life through it domain of school functioning.

Methodology A descriptive quantitative study was carried out in order to a achieve the stated objectives. The study begin from November 1st, 2011 to July 15th, 2012 A non-probability purposive (presentative) sample of Seventy (70) patients who seeking a medical care at thalassemia center in Al-Zahra teaching Hospital which included. information was collected through the use of questionnaire designed and consists of three parts, part included sociodemographic characteristics and contain (4) paragraphs and part included clinical characteristics and complications, consisting of (5) vertebrae.

Conclusion The study concluded that common thalassemia disease occurrence in people living in urban areas those of the inhabitants of rural areas. And thalassemia disease often occurs in men more than women. Study also confirmed that thalassemia affects heavily on the educational level of the individuals. The study also showed decline in the overall evaluation of the quality of life of patients.

Recommendations The study recommends to provide psychologist in the hematological units and out patient clinics is a must be present to help in providing a link between patients, school officials, the families, and the physicians and health oriented mass media should be employed for providing the population with a comprehensive information about the thalassemia.

Key wards: determination, thalassemic adolescents, quality of life

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INTRODUCTION

Thalassemia refers to life threatening diseases among children and adolescence especially those are living near the Mediterranean Sea and can cause many physical health problems, which may affect adolescent life process(1).Thalassemia is extremely stressful, and patients face a variety of school functioning. The findings also showed that culture play a major role in illness experiences(2).In addition to physical health problems, thalassemia may also affect the adolescent psychosocial aspects; there by affect the adolescent quality of life(QOL) (3).Body image alteration, decreased growth, and sexual immaturity are frequently limited

adjustment problems for older children with thalassemia (4).Adolescence, a period of psychic reorganization, which allows for new adjustments in order to face future life and reorganize experience of the past, and is one of the critical phases of existence. For the adolescent with an infirmity or chronic illness, and for his family, there are exists specific problems in addition to those encountered by a healthy adolescent. The painful realization of social, professional and relational barriers is reactivated. The feeling of failure and helplessness, somatization, impairment of self-esteem, and anger at being the victim of the unfairness of destiny, represent a supplementary affective burden for the adolescent and his family(5).Thalassemia major is a rare, complex disease. It is unrealistic to expect that practitioner with a small number of patients with thalassemia could become expert in the care of patients with this disease(6). Leisure has been identified as an important life context within which a person with chronic diseases can fulfill social roles and can participate in various activities in community. Various studies reported that ability to enjoy leisure in daily life facilitates a successful transition to integrated circumstances and help establish a satisfying life. A body of knowledge has been established to report that satisfaction with leisure is positively associated with adjustment to chronic diseases related disability (7).Quality of life is an important aspect of a complete outcomes evaluation, to document the effects of management for persons with chronic diseases and disability (8). Quality of life measurement has become an emerging science in the last few decades when QOL is a reflection of symptoms and concerns. There is now recognition that meaningful QOL measures should be use to monitor the health of the general population, estimating a burden of different conditions and monitoring outcomes (9).Also the measurement of QOL is concerned with quantifying the judgments people make to describe their experiences of health and illness (10).The assessment of changes occur in the persons QOL is part of the nursing role and the nurse is assessing patients problems regarding QOL, adherence to economics, sexual functioning, and satisfaction with therapy (11). Also the nurse should give care the family with a child who has a chronic and life threatening illnesses, with particular emphasis on the potential health problems that may affect the child's quality of life (12). Thalassemia has a negative impact on perceived physical, emotional, social and school functioning in thalassemia patients which was also found to be worse than the adolescence healthy counterparts continuing support of free desferal from the ministry of health should be given to these patients. More understanding and support especially from health authorities, and the society is essential to enhance their quality of life (13) Thalassemic adolescences showed significantly lower levels in different aspect of quality of life (14) Thalassemia in Iraq is a real problem mainly due to the deficiency in the equipments and drugs during different periods of lack of security and wars. Out of 1064 couples recruited from the Public Health Laboratory in Basra, southern Iraq, about 5% had beta-thalassemia trait and the carriers of major beta-globin disorders comprised11.48% (15)

OBJECTIVES :

To assess thalassemic adolescents′ quality of life through it domain of school functioning.

METHODOLOGY

A descriptive quantitative study was carried out in order to achieve the stated objective. The study was begun from November 1st, 2011 to July 15th , 2012.Study Sample A non-probability Purposive sample of 70 patient who seeking a medical care at thalassemia center in al –Zahra teaching hospital.

Participants a purposive sample of 70 individuals (male, and female), all of them are diagnosed as major thalassemia were enrolled in the study. Instruments an assessment tool was adopted and developed by the investigator to measure the Determination of Quality of Life for Thalassemic Adolescents in AL-Najaf AL-Ashrafe Governorate. The investigator translated the scales (Pediatric Quality of Life Inventory),from English to Arabic.Translation validity was achieved through the process of forward and backward translation, then send to the experts to review the translation experts. The final study instrument consisting of three parts. Part I: The first section was socio-demographic characteristics sheet consisted of 6 items, which included, residence, gender, age, level of education, socio economic status, Part II: clinical characteristics and complications comprised of 2 items, including complications resulting from disease, and medical history. Part III: The Pediatric quality of life inventory instruments the researcher adopted QOL scale from the world Health Organization scale to measure the variables underlying the present study and based on school domain this domain was measured through 5 items.

Data collection the collection of data were utilized of the adopted and developed questionnaire and by means of structured interview technique with the subjects who were individually interviewed in the thalassemia centers by the using of Arabic version of the questionnaire and they were interviewed in a similar way, in the same place, by the same questionnaire for all those subjects who were included in the study sample. The data collection process has been performed from April 19th, 2012 until May 19th, 2012. Each subject spends approximately (20-25) minutes to respond to the interview.

Data Analyses in order to achieve the early stated objectives, the data of the study were analyzed through the use of statistical package of social sciences (SPSS) version 17 through descriptive and inferential statistical analyses.

RESULTS

Table(1): Distribution of the Study Sample by their Demographical Characteristics

Demographical Characteristics	Groups	Frequency	Percent
Age Groups (per yrs.)	10 - 11	11	15.7
	12 - 13	22	31.4
	14 - 15	12	17.1
	16 - 17	16	22.9
	18 - 19	9	12.9
	$\bar{x} \mp S.D.$		
Gender	Male	46	65.7
	Female	24	34.3
Residence	Urban	44	62.9
	Rural	26	37.1
Level of education	Not able to read and write	4	5.7
	Able to read and write	19	27.1
	Primary school graduated	37	52.9
	Intermediate school graduated	8	11.4
	Secondary school graduated	2	2.9

Table (1) This table shows that the majority of the study sample (31.4%) fall within the second category of age (12- 13yrs).in regarding to the study subject gender, the study results indicate that the most of the them are male (65.7%). In addition to that, the study

results indicate that the most of the subjects are living in an urban residential area (62.9%). And is concerning with the study subject level of education, the study results indicate that the majority of the study subjects are primary school graduated (52.9%).

Table (2): Distribution of the Study Sample by their Responses Towards school Domain

No.	School domain	Groups	Freq.	Percent	M.S	Assessment
1	Pay attention in class	Never	36	51.4	1.59	Failure
		Sometimes	27	38.6		
		Always	7	10		
2	Forgetting things	Never	22	31.4	2.1	Pass
		Sometimes	33	47.1		
		Always	15	21.4		
3	Not leads the school	Never	38	54.3	1.61	Failure
		Sometimes	21	30		
		Always	11	15.7		
4	Missing school due to illness	Never	18	25.7	1.79	Failure
		Sometimes	19	27.1		
		Always	33	47.1		
5	Missing school to go to hospital	Never	10	14.3	1.36	Failure
		Sometimes	5	7.1		
		Always	55	78.6		
6	Difficult understanding of sailable	Never	24	34.3	1.93	Failure
		Sometimes	17	24.3		
		Always	29	41.4		

Failure = mean of score less than 2 **Pass = mean of score equal or more than 2**

Table (2) shows that the study subjects responses to the school domains were failure at all items except the forgotten things the study sample responses was pass.

DISCUSSION

Throughout the course of the present study, as shown in table (1) which refers to the statistically distribution of the observed frequencies, percentages related demographical characteristics variables for the studied sample with comparisons significant. The study results show, that the mean of the sample age is equal to 14.26 years old and that is because of the sample including the adolescents with major thalassemia 11-19 years old. Regarding to the gender, the study results indicate that the majority of the study subjects (65.7%) are male the mean age of all patients was 14.26 ∓ 2.64 .This result agree with nadir (2012) (15) showed that

the mean age was 18.78 ±2.28 years, (58.5%) were female. Regarding to the residence, it was found that the majority of the study sample(62.9%) are from urban residence. This result is supported by (16), they studied the Prevalence of β-Thalassemia Carriers Among a Cohort of University Students in Hawler Province of Iraqi Kurdistan, and their findings indicate that the majority of the study sample were urban (56.%). Concerning the level of education, most of them 52.9% are Primary school graduated. this result is similar to results obtain from study of the Quality of life assessment of children with thalassemia by (17). And in regarding to the socio-economic status, the majority of the study subjects (68.6%) are within the moderate category level of the socio-economic status. The previous studies,(18)report that the Quality of Life of School Age Thalassemic Children at Zagazig City are affected school-age children with Thalassemia Major. Also (19) the thalassaemia patients reported having significantly quality of life than the healthy controls especially in school functioning, Regarding paying attention in class that the majority of the study subjects(51.4%) show the majority of studied sample are like. (20) .Regarding school functioning,(21) explored that having to go to hospital for blood transfusion and missing school is one of the most important factors affecting the QOL of conventionally treated thalassemic patients.

CONCLUSIONS

According to the present study findings, the researcher can make the following conclusions:

The overall QOL in the adolescents with thalassemia – major under study is reduced. The school domain are the affected by disease. There is no effect of the demographic characteristics on the overall assessment of QOL. There is no effect of the medical history of the patients on the overall assessment of QOL.

RECOMMENDATIONS

Based on the study conclusion, the study can recommend that:

1. A psychologist in the center of thalassemia must be present to help in providing a link between patients, school, the families, and the physicians.
2. Health oriented mass media in providing information to population about thalassemia and other inherited diseases should be present.

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