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Assessment of Quality of Life for Patient with Thalassemia at Thalassemia Center in Thi-Qar Pronince

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Abstract:

Objective: To Assessment Quality of Life for Patient with Thalassemia at Thalassemia Center in Thi-Qar Governorate, and to identify the association between nurses' socio-demographic characteristics of age, gender, marital status, occupation and blood group and their effect to quality of life for patient with thalassemia.

Methodology: A purposive "non-probability" sample of (100) patient who were selected from thalassemia Center in Thi-qar governorate for the period from October 4th 2014 to April 1st of 2015.

Results:

The study results indicated that more than half of the sample participants are resident urban areas (58%), more than half of the sample participants were men (58%), more than half of the sample of participants are from the age group (5-10) years (54%), that the vast majority of the participants were single (91%), one-third of the sample almost with low literacy (38%), most of the sample jobless (78%) and there is a significant relationship between the quality of life and some of the variables (such as age, level education and occupation).

Recommendations: Initiate program to examine men and women before marriage to prevent thalassemia disease, the establishment of educational programs about the importance of adhering to a time treatment to reduce complications of thalassemia.

Keywords: Assessment; Quality of Life; Thalassemia.

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Introduction

Thalassemia is one of chronic illness this term derived was first described by Cooley and Lee in 1952 in several

Stated that management of patient with thalassemia is based on adequate safe blood transfusion and iron – chelating agent Used in an innovative way to

Thalassemia, at present, is one of the most challenging hematological disorder with no permanent cure. Patients' with thalassemia major disease SS-transfer needs regular blood for a living. The resulting excess iron also requires treatment Chelation therapy. Although In addition, psychological burden seen more in adolescence when the teenagers confronted with various difficulties like identity formation, developing intimate relationships and entering the working world. Acceptance and integration of thalassemia in the identity of the person becomes a difficult task at this stage. Thalassemia is challenging an individual's emotional and cognitive levels of material, and disrupts the quality of life. Frequent and complex for the treatment may also lead to the financial burden of the individual and his/her family (4).

Italian children as a severe anemia with spleen and liver enlargement, skin discoloration, and bony changes (1).

improve the QOL and ``– thalassemia. Thalassemia as disease (sign and symptom, complication, treatment effect on the daily activity of patient and effect on the QOL (2).

optimal medical management has reduced the difficulties faced by thalassemics, the psychosocial problems faced by them are now of primary importance. Developing countries such as India, the main cause of death of Thalassemia is anon-compliance with the treatment due to psychosocial factors (3).

Beta-thalassemia (β-thalassemia) is a common inherited blood disorder worldwide. Hemoglobin E/β- thalassemia is particularly common in Southeast Asia and the Indian subcontinent, As well as coastal North America, where the immigrants from Southeast Asia toa large proportion of(5).

With a 65-million0.7% withb-thalassemia trait and 17%withHBEfeature, which, an estimated 35,000 patients are living with b - thalassemia syndrome in Thailand Hb E/ β-thalassemia has a variable severity (6).

Methodology:

A purposive sample is " Non-probability" of (100) male and female participants out of 300 patients, those who were visits Thalassemia Center in Thi-Qar Governorate, were selected according specific criteria .

Administrative Arrangements:

An approval was obtained from the Ministry of Health by a contract between the Ministry of Health/ Training Center and Research Development (TCRD), and College of Nursing, and initial agreements of the Ministry of Health/Directorate Health Thi-qar Governorate, and Thalassemia Center in Thi-Qar Governorate in order to collect the required data and interviewing each subjects Thalassemia patients.

Data Collection:

Data were collected through using a questionnaire designed and developed for the purpose of the study. The questionnaire is constructed after extensive review of available literature and related studies. The study instrument consists of two parts; the first part includes participants' demographic characteristics of age, gender, level of education. The second part is related to Quality of life tool used to identify potential items for the instrument of the study. It is adopted QOL scale from the World Health Organization scale to measure the variables underlying the present study and based on (6) domains. Data were collected by the researcher are from patients, those who were visits Thalassemia Center in Thi-Qar Governorate through interview and by filling a questionnaire format.

Reliability of the questionnaire is determined through: pilot study "Cornbach's alpha" which has been (0.91) as well as the validity determined through a panel of experts in the field.

The demographic characteristic were obtained through a direct interview with each patients in the study using, adopting and developing questionnaire format. The data collection process had been performed from (4)th November 2014 until (25)th January 2015.

Statistical analysis

statistical analysis was performed using the Microsoft office excel 2007 and SPSS package (version 19). Chi- square statistics were used to determine the presence of an association between the variables. The P. value indicates that the degree of significance was ($P \leq 0.05$) to just significant result. Pearson Correlation Coefficient used to determine the relationship between the studied scales and the different socio-demographic characteristics. Cut-off-point: 1-1.66 = Low; 1.67-2.33=Moderate; 2.34-3= High; H= High; M= Moderate; L = Low. Statistical table (Frequencies & Percentages);

Results:

Table (1): Distribution of the Thalassemia Patients Socio- Demographic Characteristics

Socio-demographic characteristics(N= 100)		F	%
Living	Urban	58	58.0
	Rural	42	42.0
	Total	100	100.0
Gender	Male	58	58.0
	Female	42	42.0
	Total	100	100.0
Age	5-10	54	54.0
	16-25	37	37.0
	26-35	9	9.0
	Total	100	100.0
Marital Status	Single	91	91.0
	Married	6	6.0
	Widowed	1	1.0
	Separated	2	2.0
	Total	100	100.0
Level of education	Illiterate	38	38.0
	Reads and writes	31	31.0
	Primary	13	13.0
	Intermediate	8	8.0
	Preparatory	6	6.0
	College	4	4.0
	Total	100	100.0
Occupation	Employees	5	5.0
	Free works	9	9.0
	Housewife	8	8.0
	Job less	78	78.0
	Total	100	100.0
Monthly Income	Insufficient	49	49.0
	Somewhat Sufficient	50	50.0
	Sufficient	1	1.0
	Total	100	100.0
Blood group	A-	8	8.0
	A+	21	21.0
	AB+	4	4.0
	B+	26	26.0
	O-	2	2.0
	O+	39	39.0
	Total	100	100.0

F. Frequency %: percentage N: participants

This table shows that the majority of the study sample was living in urban residential area (58%) of the completely sample. The above table also shows that more than half study subjects (58%) were males. In addition, the major group of the study sample was within age group (5-10) years (54%). In regarding to the subjects marital status, the majority of the study sample were single (91%). Also in regarding to the subjects levels of education, the results show that the majority of the study sample was illiterate (38%). In addition, more than half study sample in regarding to their occupational status was jobless (78%). Also in regarding to the subjects Monthly Income, the results show that half of the study sample was Somewhat Sufficient (50%). Finally, in the above table and in regarding to the subjects Blood group, the results show that less than half group of the study sample were within the Blood group (O+); (39%).

Table (2): Summary statistics for the Main Domains of the Quality of Life by their Mean of Scores

Main Domains of the studied questionnaire	**M.S.**	**Ass.**
Physical domain	1.49	L
Psychological domain	1.40	L
level of independency Domain	1.97	M
Socialdomain	1.81	M
Environment Domain	1.23	L
Spiritual domain	1.52	L
Overall Measures of Quality of Life Domains	1.57	L

F: frequencies, %: percentages, M.S.: mean of scores. Ass.: Assessment of scores cut off point: (0.66),cut off point intervals (1-1.66):low, (1.67-2.33): moderate, and (2.34-3): high

Table (2) shows the summarizes of the subjects responding at the main domains levels, that were done by using mean of score (MS).In the light of cutoff point (0.66) the results show in regarding to the overall responses of the physical domain are low. In addition, the overall responses to the psychological domains were low. Moreover, the responses to the level of independence sub-domain were moderate. In addition, the responses to the social domains were moderate responses at the overall social main domain. Regarding to the environmental domains the responses were low at the environmental main domain. Finally, in this table the responses to the spiritual domains were low. In addition, the overall responses to the quality of life main domains were low.

Table (3) Association between Study Variables

Study variable	Living	Gender	Age	Marital Status	Level of education	Occupation	Monthly Income
physical domain	-.159-	-.002-	.222*	.035	.140	-.070-	.034
Psychological domain	-.062-	-.033-	.382**	.149	.145	-.128-	-.113-
independency domain	-.113-	-.093-	.093	.068	.251*	-.222-*	-.025-
Social domain	-.303-**	-.099-	.377**	.005	.573**	-.292-**	.050
Environment domain	-.035-	.123	.102	-.115-	-.010-	-.012-	.127
Spiritual domain	.016	.046	.344**	.298**	.109	-.111-	-.002-
Spiritual NEG	-.204-*	.056	.479**	.092	.409**	-.257-**	-.093-
Quality of Life Domains	-.145-	-.015-	.371**	.051	.204*	-.112-	-.043-

***. Correlation is significant at the 0.05 level (2-tailed).**

****. Correlation is significant at the 0.01 level (2-tailed).**

Table (3) demonstrates that participants age and physical domain positively correlate with occurrence of physical effects (*r*= .222; *P<0.05*). In addition, participants age and Psychological domain positively correlate with occurrence of Psychological effects (*r*= .382; *P<0.01*). However, independency domain positively correlate with the Level of education (*r*= **.251***; *P<0.05*); While independency domain negatively correlates with occupation (*r*= -.222; *P<0.05*). participant living and social domain negatively correlate with occurrence of social effects (*r*= -.303-**; *P<0.01*); while participants age and social domain positively correlate with occurrence of social effects (*r*= . .377**; *P<0.01*); in addition participants level of education and social domain positively correlate with occurrence of social effects (*r*= .573**; *P<0.01*) and participant occupation and social domain negatively correlate with occurrence of social effects (*r*= -.292-**; *P<0.01*). Participants age and spiritual domain positively correlate with occurrence of spiritual effects (*r*= .344**; *P<0.01*) *and* participants marital status and spiritual domain positively correlate with occurrence of spiritual effects (*r*= .298**; *P<0.01*). participant living and spiritual NEG domain negatively correlate with occurrence of spiritual lNEG effects (*r*= -.204-*; *P<0.05*), participant age and spiritual NEG domain positively correlate with occurrence of spiritual NEG effects (*r*= .479**;*P<0.01*), participant level of education and spiritual NEG domain positively correlate with occurrence of spiritual NEG effects (*r*=.409**;*P<0.01*) and participant occupation and spiritual NEG domain negatively correlate with occurrence of spiritual NEG effects (*r*=-.257-**;*P<0.01*).Furthermore, participants age and Quality of Life Domains positively correlate (*r*= . .371**; *P<0.01*) *and* participants level of education and Quality of Life Domains positively correlate (*r*= . . 204*;*P<0.05*).

Table (4) Association between Quality of Life Domains of Patients with Thalassemia and their Age Group

QOL **Age**		**Quality of Life Domains**			**Total**
		Always	**Sometime**	**Never**	
Age	5-10	40	14	0	54
	16-25	30	7	0	37
	26-35	4	4	1	9
Total		74	25	1	100
χ^2obs. = 13.351		χ^2crit. = 9.4877	df=4	P< 0.05	S

χ^2obs. : chi-square observed, χ^2crit: chi-square critical, df: degree of freedom, p : probability value, P< 0.05: significant, P >0.05: non-significant

This table indicates a significant association between quality of life domains of patients with Thalassemia and their age group.**Table (5) Association between Quality of Life Domains of Patients with Thalassemia and their Level of Education**

QOL Level of education		Quality of Life Domains			Total
		Always	Sometime	Never	
Level of education	Illiterate	35	3	0	38
	Reads and writes	21	10	0	31
	Primary	6	6	1	13
	Intermediate	5	3	0	8
	Preparatory	3	3	0	6
	College	4	0	0	4
Total		74	25	1	100
χ^2obs.= 21.305		χ^2crit. = 18.307	df=10	P< 0.05	S

χ^2obs. : chi-square observed, χ^2crit : chi-square critical , df: degree of freedom, p : probability value, $P< 0.05$: significant, $P >0.05$: non-significant

This table presents a significant association between quality of life domains of Thalassemia patients and their level of education.

Table (6) Association between Quality of Life Domains of Patients with Thalassemia and their Occupation

QOL Occupation		Quality of Life Domains			Total
		Always	Sometime	Never	
Occupation	Employees	4	0	1	5
	Free works	5	4	0	9
	Housewife	7	1	0	8
	Job less	58	20	0	78
Total		74	25	1	100
χ^2obs. = 22.760		χ^2crit. = 12.591	df=6	P< 0.05	S

χ^2obs. : chi-square observed, χ^2crit : chi-square critical , df: degree of freedom, p : probability value, $P< 0.05$: significant, $P >0.05$: non-significant

A significant association was determined between quality of life domains of Thalassemia patients and their occupation.

Discussion:

The findings of the present study show that the majority of the sample (58%) living at urban residential areas. This result comes along with Amare et. al., their findings indicate, that the majority of the study subjects were living in urban areas (61.8%). The appearance of a high proportion of patients with thalassemia who live in urban areas as a result of migration from rural to urban areas, as well as a result of thalassemia in order to be close to reduce the burden of compliance with treatment (8).

Regarding to gender, the findings indicate that the more than half study sample (58%) were male. This result comes along with Othman et. al., show that the majority of the study subjects were male (57.4%) (9).

Relative to the age groups, about more half of the study sample (54%) was within (5-10) years, this result does not mean that the peak incidence age of thalassemia disease was within (5-10) years, but perhaps because of family interest and commitment to taking the therapy make an appearance this age group is most.

Regarding to marital status, the majority of study sample (91%) were single. This result agrees with the Masood et. al., they studied the factors influencing quality of life in patients with thalassemia in Pakistan, their findings indicate, that the majority of the study sample were single (78.3%). The appearance of the high proportion of single is because most of the participants are in the age group (5-10 years) and this is resulting in a higher proportion of single addition to the problem of the disease (10).

Concerning with educational levels, less than half study sample were illiterate (38%). This result comes along with Dhuriaet. al, the findings of study indicate, that nearly half study subjects were illiterate (48%). Peoples who were not educated, more vulnerable to disease than others, because of insufficient of health awareness, which leads to non-compliance to vaccines, treatment, health advices, guidance, and health programs. This result of mental disability that affects thalassemia patients in addition to most of the participants are in the age group (5-10) years (11).

Regarding occupational status, the majority of the study sample were jobless (78%). This result agrees with Hossain et. al., they found that more than one-third of the study subjects were jobless (41%). This result is due to that most of the participants are children do not hold certificates entitling them to appoint as well as disease disability (12).

Regarding to Monthly Income about half of the study sample were Somewhat Sufficient(50%).This result is due to the large number of revisions to private clinics, doctors in addition to the purchase of medicines and the special needs of patients.

Finally, regarding blood group, the majority of study sample were O+ (39%). This result is due to this species is the highest in the province.

Regarding age groups the results show that there was a significant association between age groups and the quality of life domains of patients with thalassemia. This result supported by Leak et. al., their findings indicate that a significant association between quality of life of thalassemia patients and their age groups (13).

Regarding levels of education, the study results show that there was a significant association between level of education and quality of life domains. This result supported by Adeyeye et. al., their findings indicate that there was a significant association between the level of education and quality of life domains (14).

In addition, the results show that there was a significant association between occupational status and quality of life domains. This result supported by, Al-Jadid et. al., they reported that there was a significant association between occupational status and quality of life domains (15).

Recommendations:

Initiate program to examine men and women before marriage to prevent thalassemia disease. The establishment of educational programs and audio-visual means to aware people about of the seriousness of the thalassemia disease. The establishment of educational programs about the importance of adhering to a time treatment to reduce complications of thalassemia. Educating the patient and his family to provide appropriate environmental conditions to reduce simple and acute disease because of the lack of patient's immune system. Stay away from inbreeding. The establishment of a special technique to examine blood before giving the patient to prevent the transmission of diseases such as AIDS and the hepatitis C….etc.

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المستخلص:

الهدف: لتقييم نوعية حياة مرضى الثلاسيميا المراجعين لمركز الثلاسيميا في محافظة ذي قار وللتعرف على العلاقة بين الخصائص الاجتماعية والديموغرافية للمرضى مثل العمر، الجنس، الحالة الاجتماعية، المهنة ، و فصيلة الدم و وتأثيرها على نوعية حياة مرضى الثلاسيميا .

المنهجيـة: عينة غرضيه غير احتمالية تتألف من (100) مريض تم اختيارهم من مركز الثلاسيميا في محافظة ذي قار للفترة من الرابع تشرين الأول ٢٠١٤ لغاية ١ من نيسان ٢٠١٥ .

النَتائِـج: أظهرت نتائج الدراسة الحالية أن أكثر من نصف العينة المشاركين هم من سكنة الحضر وبنسبة (٥٨%)، أكثر من نصف العينة المشاركين هم من جنس الرجال (٥٨%) ، أكثر من نصف العينة المشاركين هم من الفئة العمرية (٥-١٠) سنوات (٥٤%)، ان الغالبية العظمي للمشاركين كانوا غير متزوجين (٩١%) ، ثلث العينة تقريبا لا يجيدون القراءة والكتابة(٣٨%)، اغلب أفراد العينة لا يمتهنون أي مهنة (٧٨%)، هنالك علاقة بين نوعية الحياة وبعض المتغيرات مثل (العمر ، مستوى التعليم و المهنة).

التوصيات: أوصت الدراسة ببدء برنامج لفحص الرجل والمرأة قبل الزواج للوقاية من مرض الثالاسيميا. إنشاء البرامج التعليمية حوله لأهمية الالتزام علاج الوقت للحد من مضاعفات مرض الثلاسيميا.