Quality Of Life For Caregivers` Of Children With Congenital Heart Disease In Surgical Specialty Hospital – Cardiac Center Kurdistan Region/Iraq

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الخلاصة :

الهدف: تهدف الدراسة لتقييم جوانب نوعية الحياة (بدني ، إجتماعي ،نفسي وروحي) لمقدمي الرعاية الذين لديهم أطفال يعانون من التشوهات الخلقية القلبية وعلاقتها ببعض المتغيرات في المستشفى الجراحة التخصصية-مركز القلب/ إقليم كردستان/العراق

المنهجية :أجريت دراسة وصفية في المستشفى الجراحة التخصصية-مركز القلب/ إقليم كردستان/العراق للفترة ما بين (الأول -تموز -2009 ولغاية لنهاية أيلول -2010) اختيرت عينة غير احتمالية (غرضيه)(200) من مقدمي الرعاية للأطفال المصابين بإمراض القلب الخلقية أعدت استمارة أستبيانية تضمنت ثلاثة أجزاء(المعلومات الديموغرافية الاجتماعية ، المعلومات الطبية) لمقدمي الرعاية و أطفالهم ،وأسئلة تم إعدادها من قبل (منظمة الصحة العالمية،1998 لتقييم نوعية الحياة المصابين بالحالات الحرجة. تم تحديد الثبات والمصداقية للأسئلة من خلال حساب عامل الارتباط الفا (0,912) والتي اجريت ل(10)ا من مقدمي الرعاية ولتحقيق المصداقية للأسئلة فقد تم تحقيقها من خلال مجموعة من الخبراء ذوي الاختصاص وعددهم (21) خبيرا". تم تحليل البيانات باستخدام التحليل الإحصائي الوصفي (التكرارات،النسبة المئوية،الوسط الحسابي) والتحليل الإحصائي الأستنتاجي (مربع كآي).

النتائج : شارت الدراسة ان الأطفال المصابين بالتشوهات الخلقية القلبية لهم تأثير كبير على كل جوانب نوعية حياة لمقدمي الرعاية بوجود علاقة ذات دلالة إحصائية ما بين الخصائص الديموغرافية الاجتماعية لمقدمي الرعاية للأطفال المصابين بالتشوهات الخلقية القلبية ونوعية حياتهم ك(المربي الرئيسي للطفل، العمر،الحالة الزوجية ، المهنة، الحالة الاجتماعية، شدة إصابة بالمرض).

الاستنتاج: : استنتجت الدراسة بأن غالبية مقدمي الرعاية هن أمهات وربات البيوت،تتراوح أعمارهن ما بين (35- 26) سنة، من المناطق الحضرية، لديهن ≤ 3 سنوات من التعليم الابتدائي ومن المستوى الاجتماعي والاقتصادي المنخفض. وكانت غالبية مقدمي الرعاية يعانون من كافة جوانب نوعية حياة لمقدمي الرعاية (المادية والنفسية والاجتماعية والروحية)

التوصيات :أوصت الدراسة ببناء وتطبيق برنامج تثقيفي لمقدمي الرعاية الأطفال المصابين بالتشوهات الخلقية القلبية وقيام بدراسة أوسع حيث لتشمل عدد اكبر من لمقدمي الرعاية لتحديد مشاكلهم والإسهام في التحسين نوعية حياتهم من خلال تحسين الرعاية.

Abstract

Objective: The study aims to assess quality of life for caregivers who have children with congenial heart disease in Surgical Specialty Hospital - Cardiac Center in Erbil city.

Methods: Descriptive design of study was carried out in Surgical Specialty Hospital - Cardiac Center in Erbil city from first of July 2009 to end of September 2010. A purposive sample of (200) caregivers for children with congenital heart disease were selected. The tool is consisting of three parts questionnaire format (Socio-demographical characteristic and medical data) of caregivers and children, and tool for assessment the quality of life adapted from WHO was used for data collection, (WHO-QOL,1998).A few modifications were done with the tool, The validity of the study questionnaire was determined initially through a panel of (21) experts. Determination of reliability of the total QOL Alpha correlation coefficient was computed and indicated was (0.912).The data were analyzed through using by Excel and SPSS version17 programmed.

Results: The findings of the study indicate that the caregivers had been affected in all domains of quality of life and there is a significant association between socio-demographic characteristics (main caregivers, age, marital status, occupation, residential area, socio-economic and severity of disease) with quality of life domains, but there were no association between **level** of education and quality of life domains.

Conclusions: Most of the caregivers were mothers and housewives, their age groups were between (26-35) years old, were from urban areas, have ≤ 3 years of formal education and from low socio-economical level. And the majority of caregivers were suffering in (physical, psychological, social and spiritual) domains.

Recommendation: The study recommends to establish the psychological unit ،Implementation of an educational program for those caregivers of children with CHD.

Keywords: Quality of life, Caregivers, Children, Congenital Heart Disease ,Domains

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INTRODUCTION

Congenital heart diseases it is the most common group of structural malformations in children[1].The incidence of CHD in children is approximately 5-8 in 1000 live births[2]. And it is accounting for 70%-80% of all pediatric heart

disease[3]. Congenital heart defects are the second leading cause of death in infancy, result from abnormal cardiovascular development during fetal life that obstruct or alter blood-flow patterns. Defects are classified as either cyanotic or a cyanotic[4]. Mothers within all parent groups had higher levels of distress and hopelessness than fathers, with the highest levels among mothers of children with CHD compared to mothers in the other groups. Fathers of children with CHD were doing worse than fathers belonging to the other groups. When caring for children with congenital heart disease, caregivers tend to suffer from social isolation and work-related functions [5]. Quality of Life among parents of disabled children are contradictory, in addition little is known about the identification and quantification of determinants of QoL among parents of children with heart diseases[1]. The number of studies conducted is very scarce in developing country and there was only one study carried out in Egypt, 2008. And there is no any study conducted in Iraq and Kurdistan Region.

Aim of the study:

To assess the quality of life (physical, psychological, social and spiritual) domains and its association with some socio-demographic characteristics of caregivers.

Subjects and methods:

A descriptive study conducted in Surgical Specialty Hospital/ Cardiac Center in Kurdistan Region/Iraq from first of July 2009 to the end of September 2010. A purposive sample of (200) caregivers of children with congenital heart disease were selected. The questionnaires consists of socio-demographic characteristic of caregivers and their children, and standardized QoL questionnaire from WHO1998[6]. Domains of Quality of Life consists of four domains:-

A–Physical Domain: It consists of four parameters as follow general health (4 sub items), pain and discomfort (3 sub items), energy and fatigue (3 sub items) and rest and sleep (4 sub items).

B- Psychological Domain: It consists of four parameters as follow appearance and body image (2 sub items), thought (3 sub items), concentration, memory, and learning (2 sub items); and negative feelings (5 sub items). C- Social Relationship Domain: It consists of four parameters as follow interpersonal relationship (5 sub items), social support (3 sub items), financial status (7 sub item); and recreation (3 sub items).D-Spirituality, Religion, and Personal Belief domain: It consists of (5 sub items) which assesses the impact of children with CHD on caregiver's spirituality, religion and personal belief. The domains of quality of life for Caregivers of children with congenital heart disease were scored and rated by the three alternative answers (likert scale) as always =3, sometimes=2, never=1 (Polit and Hunger 1999).The higher score of the questionnaire indicates greater than the effect of the chronic disease and therapy on QOL of caregivers. The criteria of the sample selection including to:1-Inclusion criteria: a- child diagnosed with the Congenital Heart Disease for at least 1year and attending the center for treatment or follow up .b- Both genders their age was (≤ 18)years2- Exclusion criteria: a- A child age less than one year .b-A child diagnoses of Congenital Heart Disease for less than one year .c-A Down syndrome child with congenital heart disease. Data was collected through use of tool questionnaire through direct method (face to face) interview with caregivers of children with Congenital Heart Disease and who kindly accepted to participate in the study. The Investigator use following instrument during the data collection; Sphygmomanometer: A mercury sphygmomanometer (Mercuro 300mmhg), (ALPK2.22, 32cm, Tokyo. Japan) and stethoscope (Japan) are used for measuring the blood pressure of caregivers. The blood pressure is classified according to the (National Heart Lung and Blood Institute,

2008 Digital Scale: Are used to measure the weight to detect the BMI of caregivers (Scale Beurer CE, Art-Nr.753.05 type GS 34). The MBI are classified according to the (CDC, 2000), Tab Measure: Are used to measure the height of caregiver. The data collection started from 7th of January 2010 to 10th of April 2010.Data were analyzed by Excel and SPSS version17 programme through the application descriptive statistical data analysis (Frequencies, percentage, mean of score) and inferential statistical data analysis (Chi – Square). Mean of Score ≥ 2 = Suffering Mean of Score < 2= Not Suffering

RESULTS:

Table (1):Demographic characteristic of Caregivers for children with congenital heart disease

socio-demographical Characteristics of caregivers		F n.=200	%
Main Caregiver	Mother	128	64.0
	Father	42	21.0
	Sister	3	1.5
	Brother	2	1.0
	Aunt	6	3.0
	Uncle	7	3.5
	Cousin	2	1.0
	Grandmother	10	5.0
Age	16-25 years	34	17.0
	26-35years	78	39.0
	36-45 years	62	31.0
	46-55 years	22	11.0
	56-65 years	3	1.5
	≥ 66 years	1	0.5
Gender	Male	53	26.5
	Female	147	73.5
Level of education	Primary school or illiterate	147	73.5
	Intermediate school	27	13.5
	preparatory school	10	5.0
	College school	8	4.0
	High education	8	4.0
Caregivers Occupation before Child's Diagnoses	Non Governmental occupation	30	15.0
	Governmental occupation	36	18.0
	Housewives	120	60.0
	Unemployed	2	1.0
	Student	5	2.5
	Retired	7	3.5
Caregivers Loss of Job after Child's Diagnoses	Yes	16	44.4
	No	20	55.6
Marital Status	Married	184	92.0
	Divorced	1	0.5
	Separated	3	1.5
	Widowed	10	5.0
	Single	2	1.0
Residential Area	Urban	118	59.0
	Sub urban	46	23.0
	Rural	36	18.0
Governorate	Hawler	78	39.0
	Sulaimania	31	15.5
	Dohuk	59	29.5
	Kirkuk	20	10.0
	Musil	12	6
Socio-economic Status	Low	103	51.5
	Moderate	92	46.0
	High	5	2.5

Table (1) show that most of caregivers (64%) were mothers, (21%) were fathers, while (1%) of them were brothers .Regarding the age, (39%) were within the age group (26 - 35) years old, while the lowest percentage (0.5%) were (66) years. (73.5%) was female, while (26.5%) were male ,(44%) of caregivers was graduate from primary school or illiterate, while (4%) of them have high level **of** educations.In respect to their occupational status of caregivers before the child's CHD diagnosis shows that (60%) were housewives, (18%) were governmental occupation, (15%) have free jobs, (3.5%) were retired, (2.5%) were students and the other (1%) were the unemployed.Concerning their occupational status, after the child diagnosis, shows (44.4%) were losing their jobs, (55.6%) of them were stay in their jobs.(92 %)of them were married (not separated), (5%) were widowed, (1.5%) were separated, (1%) were single and only (0.5%) were divorced.Concerning the residential area, it shows that the highest percentage of the sample (59%) were from urban areas, (23%) were from sub urban area, while only (18%) of them were from rural areas. Concerning the Governorate (39%) of them were from Erbil, (29.5%) from Dohuk, (15.5%) from Sulaimania, (10%) from Kirkuk, and (6%) from Musil. Regarding to socioeconomic status shows that the highest percentage of the sample (51.5%) were low socioeconomic level and (46%) were moderate in socioeconomic level, while only (2.5%) were high socioeconomic level.

Table(2):Demographic characteristics of children with congenital heart disease.

Childs Socio-demographical Characteristics		**F** **n =200**	**%**
Child`s Age	1-3 years 4-5 years 6-12 years 13-18 years	85 30 63 22	42.5 15.0 31.5 11.0
Gender	Male Female	103 97	51.5 48.5
Attendance to school	Regular attendance Irregular Not attending than	54 33 113	27.0 16.5 56.5
Achievement in the school	Excellent Good Bad	7 26 21	12.96 48.14 38.88
	Total	**54**	**100**

Table (2) shows that the highest percentage of the sample (42.5%) were (toddler) within the age group (1-3) years old, (31.5%) were (school age) within the age group (6-12) years, (15%) were (preschool age) within the age group (4-5) years, and the lowest percentage (11%) were (adolescent) within the age group (13-18) years.Concerning the child gender, shows that more than half of children (51.5%) were males and (48.5%) of them were females.Regarding Child`s attendance to school, (56.5%) were not attend to school, (27%) were regular attending to school and (16.5%) of them couldn`t attend the school.Concerning the Child`s achievement in the school, (48.14%) were good in the school achievement, (38.88%) of child's were bad, only (12.96%) of them were excellent in the school achievement.

Table (3) Physical Domain for Caregivers having Children with Congenital Heart Disease

Physical Domain	Always (3)		Sometime (2)		Never (1)		Total		Mean Score
	F	%	F	%	F	%	n600*	%	
General Health									
Increase physical activities	486	81.0	56	14.0	10	5.0	552	100	2.76
Affects health status	378	63.0	110	27.5	19	9.5	507	100	2.76
Lost weight	114	19.0	122	30.5	101	50.5	337	100	2.76
Loss or decreased of appetite	102	17.0	96	24.0	118	59.0	316	100	2.76
Pain and Discomfort									
headache	378	63.0	88	22.0	30	15	496	100	2.48
backache	243	40.5	112	28.0	63	31.5	418	100	2.48
generalized pain	60	10.0	40	10.0	160	80.0	260	100	2.48
Energy and Fatigue									
Feel tired when taking care of your child	495	82.5	58	14.5	6	3.0	559	100	2.80
Feel tired when you do simple activities	216	36.0	120	30.0	68	34.0	404	100	2.80
Feel tired when you stay with your child in hospital	423	70.5	80	20.0	19	9.5	522	100	2.80
Rest and Sleep									
Decreased rest time	486	81.0	66	16.5	5	2.5	557	100	2.79
Nap during day	105	17.5	82	20.5	124	62.0	316	100	1.56
Sleep disturbance	327	54.5	60	15.0	61	30.5	448	100	2.24
Use any drug for sleeping	21	3.5	36	9.0	175	87.5	232	100	1.16

This table shows that the mean scores high 2.80 in sub title of energy and fatigue, (feeling tired when taking care of child, feeling tired when you do simple activities, and feeling tired when you stay with a child in hospital) respectively for caregivers that means they were suffering. also in sub title of rest and sleep (rest time has decreased) they report high mean score 2.79 that means they were suffering.

Table (4) Psychological Domain for Caregivers having Children with Congenital Heart Disease.

Psychological Domain	Always (3)		Some Time (2)		Never (1)		Total		Mean Score
	F	%	F	%	F	%	*600	%	
Appearance and Image									
acceptable appearance by others	72	12.0	82	20.5	135	67.5	289	100	1.45
appearance is changed	141	23.5	88	22.0	109	54.5	338	100	1.69
Thought									
child`s condition is better now	381	63.5	44	11.0	51	25.5	476	100	2.38
child's future	558	93.0	22	5.5	3	1.5	583	100	2.92
disability of child	555	92.5	28	7.0	1	0.5	584	100	2.92
Concentration, Memory, and Learning									
loss of memory	261	39.0	116	29.0	64	32.0	441	100	2.07
loss of concentration	150	25.0	150	37.5	75	37.5	375	100	1.88
Negative feelings									
Feel sad	525	87.5	42	10.5	4	2.0	571	100	2.86
Stay alone	279	46.5	78	19.5	68	34.0	425	100	2.13
Lose temper easily	297	49.5	90	22.5	56	28.0	443	100	2.22
Anxiety frequently	276	46.0	128	32.0	44	22.0	448	100	2.24
Cry sometimes when child`s unable to express his feelings	120	20.0	294	73.5	13	6.5	427	100	2.14

Table (4) show, high mean of score 2.92 of sub-item of thought (thinking that her child

condition is better now, thinking a lot about child's future and about the disability of the child). and in concentration, memory, they reported high mean score 2.80, specially of sub-item loss of memory. Revealed that the majority of the study sample were suffering

Table (5) Social Domain of Caregivers of Children with Congenital Heart Disease.

	Always (3)	Some Time (20)		Never (1)			Total	Mean Score
Social Relationship Domain	**F**	**%**	**F**	**%**	**F**	**%**	**F**	**%**	
Interpersonal Relationships									
Relationship with family members negatively changed	183	30.5	78	19.5	100	50.0	361	100	1.81
Marital relationship been better now	264	44.0	72	18.0	76	38.0	412	100	2.06
Lost relation with friends	165	27.5	66	16.5	112	56.0	343	100	1.72
Lost social interaction	318	53.0	172	43.0	8	4.0	498	100	2.49
Neglect other children at home	327	54.5	138	34.5	22	11.0	487	100	2.44
Social support									
Feel restricted responsibilities	312	52.0	162	40.5	15	7.5	489	100	2.45
Anyone help you in taking care of your child	57	9.5	176	44.0	93	46.5	326	100	1.63
Supporting by organization or society center	36	6.0	62	15.5	157	78.5	255	100	1.28
Financial Status									
financial difficulties	441	73.5	38	9.5	34	17.0	513	100	2.57
support financially by relatives / friends	354	59.0	44	11.0	60	30.0	404	100	2.29
Bought some of house equipment for your child care	248	41.0	94	23.5	71	35.5	411	100	2.06
cardiac center far away from house	393	65.5	12	3.0	63	31.5	570	100	2.34
Treatment was expensive	543	90.5	16	4.0	11	5.5	270	100	2.85
The medical services in our country enough to cover the CHD	501	83.5	52	13.0	7	3.5	560	100	2.80
Kurdistan Government financially support the family with Children of CHD	231	38.5	48	12.0	99	49.5	378	100	1.89
Recreation									
Reduced your social activities	504	84.0	58	14.5	3	1.5	565	100	2.83
Able to do many things that like to do	69	11.5	86	21.5	134	67.0	275	100	1.45
spending less time than before with your family	333	55.5	158	39.5	10	5.0	501	100	2.51

Table (5) show that high mean scores 2.85 of sub item (Treatment was expensive) related to financial status and high mean score 2.80of sub item (The medical services in our country enough to cover the CHD)also they reported in recreation high mean score 2.80 of sub item(reduced their social activities) .Revealed that the majority of the study sample were suffering

Table (6) Spiritual domain for caregivers having children with congenital heart disease

Spirituality, Religion and Personal Belief Domain.	Always (3)		Sometime (2)		Never (1)		Total		Mean Score
	F	%	F	%	F	%	*600	%	
Reduced religious activities	273	45.5	130	32.5	44	22.0	447	100	2.24
Think that your child condition as examining situation	324	54.0	160	40.0	12	6.0	496	100	2.48
Religion is important	429	71.5	90	22.5	12	6.0	531	100	2.66
Satisfactions about life is changed after your child's illness	93	15.5	137	34.0	101	50.5	331	100	1.65
Relax when you are in communication with God	423	70.5	76	19.0	21	10.5	521	100	2.5

This table show that the mean of scores of items (feel that religion is important to you and you think that your child condition as an examining situation) were high mean score 2.66 and 2.48 respectively .that mean that the caregiver were suffering .

Table (7) Assessment of Caregiver's rate for their overall QOL.

At the end how would you rate your overall quality of life?	Worse possible (1)	Poor (2)	Fair (3)	Good (4)	Best possible (5)
No.	58	208	90	24	10
Percentage	29	52	15	3	1

This table shows that more than half of the caregivers (52%) their QOL was poor, (29%) of the their QOL was worse.

Table (8): Association between the caregiver's demographic characteristics and domains of uality of life:

Variable	Domains of quality of life	P. Value	Decision
Caregivers	Physical domain	0.543	Non Significant
	Psychological domain	0.044	**Significant**
	Social domain	0.136	Non Significant
	Spiritual domain	0.529	Non Significant
Caregivers age	Physical domain	0.001	**Highly Significant**
	Psychological domain	0.044	**Significant**
	Social domain	0.136	Non Significant
	Spiritual domain	0.529	Non Significant
Marital Status	Physical domain	0.02	**Significant**
	Psychological domain	0.940	Non Significant
	Social domain	0.001	**Highly Significant**
	Spiritual domain	0.870	Non Significant
Residential area	Physical domain	0.419	Non Significant
	Psychological domain	0.322	Non Significant
	Social domain	0.002	**Highly Significant**
	Spiritual domain	0.964	Non Significant
Socio-economic status	Physical domain	0.126	Non Significant
	Psychological domain	0.788	Non Significant
	Social domain	0.001	**Highly Significant**
	Spiritual domain	0.983	Non Significant
Level of education	Physical domain	0.166	Non Significant
	Psychological domain	0.159	Non Significant
	Social domain	0.117	Non Significant
	Spiritual domain	0.956	Non Significant
Severity of Congenital Heart Disease	Physical domain	0.001	**Highly Significant**
	Psychological domain	0.041	**Significant**
	Social domain	0.039	**Significant**
	Spiritual domain	0.427	Non Significant

Table (8) show that there is significant association between the main caregivers,

caregiver's age and marital status with (physical and psychological) domains. But a highly significant association is seen between the (caregiver's age, marital status residential area, socio-economic status and severity of Congenital Heart Disease of the child) with (physical, psychological and social) domains of quality of life at p.vaule <0.05.

DISCUSSION:

The findings of the present study revealed that most of caregivers were mothers, this existing study result is similar to that done in Thailand[3], the aim of his study was to find out the factors influencing the burden experienced by the caregivers of children with CHD, and the study showed that the majority of the caregivers were mothers. Regarding the age, the highest percentage of the sample were within the age group (26 - 35) years old, this existing study result is similar to study done in Tutkey[7], the purpose of their study was to determine the distress levels of parents of children with CHD and identify factors that influenced the levels of distress, the study also stated that most of the caregivers were in middle age, which is similar to the present study findings. Regarding the educational status of caregivers, half of the sample was graduate from primary school or illiterate. The findings come along with in Tutkey[7], their results indicate that 52.3% were illiterate and graduates of primary school. In respect to caregiver's occupational status, the present study indicated that most of them were housewives; this existing result is similar to study done in Germany[8] , the study showed that the majority of the caregivers were housewives, and it was similar to the study findings. Concerning the marital status, it has shows that the majority of the samples were married. This is agreeing with the study done in Egypt[1] show that the majority of the sample is married, which is similar to the present study findings. Regarding to socio-economic status, the highest percentage of the sample was coming from a low socio-economic class. The finding comes along with study done in Tutkey[7] in which their result indicates that 47% of the sample has financial difficulties. Regarding the child`s age, the highest percentage of the samples were (toddler) within the age group of (1-3) years. The findings are **agree with** the study done in Thailand [3] , which results that 51.5% of child's age was between 1-2 years old and this is consistent with the present study finding. This finding agreed with study done in Egypt[1] showed that the majority of children with CHD were in toddler.Concerning the child`s gender, more than half of sample were male. **agree with** the finding reported in Tutkey[7] was indicated that (48.3%) of children was male and this is agreed with the study finding. The mean scores of energy and fatigue of caregivers in sub items (feel tired when taking care of child, feel tired when do simple activities and feel tired when stay with child in hospital) were suffering. the finding is agreed with study[(8)] their results indicates that the parents of the children with CHD have severe impairment across multiple domains of QOL including a lowered sense of well-being and energy. Also this finding is consistent with Canadian[(9)]study reported that living with children have heart disease has a negative influence on a parent's ability and their activity, continues care and follow up of the child with CHD affect on parental activity. Concerning sleep and rests, the results reported that the caregivers were suffering in sub decreased rest time the result was supported by by a study [(10)] report that the caregivers of children with CHD may have changes in sleep patterns.

Regarding the thought in psychological domain the mean score of sub items (thinking that your child condition is better now, thinking a lot about your child's future and thinking a

lot about the disability of your child) were high that means most of the caregivers were suffering. The finding is similar with[11] a study mentioned that the children`s parent with heart disease thought that the heart disease made their children handicapped. also they suffering in Concentration their memory the finding is supported by[12] a study which finding the caregivers of sickle cell disease patients had a lower QOL on the subscale decreased cognitive performance. In financial status of social domain found that sub items the treatment was expensive and the medical services in our country are not enough to cover the CHD) were high in mean score they suffering. These finding is similar to[13] whose result shows that the mothers of children with congenital anomaly were suffering financial problems. also they reported in recreation high mean score 2.80 of sub item(reduced their social activities) .Revealed that the majority of the study sample were suffering these findings come along with[14] show that the caregivers of children with CHD are suffering from social burden and financial burden. Also it is supported a study,[15] in France; they found that the children with the complex CHD may have extensive problems that affect the parental stress, such as dependent lifestyle, social problems, and less leisure activity. In spiritual domain fond that the care givers were suffering in sub items ,feel that religion is important and they think about their child condition as an examining situation. Regarding the finding inconsistent with, [16] whose result indicated that the parents of children with CHD did not endorse any items relative to the spiritual aspect of QOL, yet this dimension has been shown to be important in other patient populations. Regarding the spiritual domain, the mean score of items (religious activities are reduced, feel relax when you are in communication with God, feel that religion is important to you and think that your child condition as examining situation) was suffering. the finding inconsistent with' [8] whose result indicated that the parents of children with CHD did not endorse any items relative to the spiritual aspect of QOL, yet this dimension has been shown to be important in other patient populations. There is significant association between the main caregivers of the sample and the psychological domains of quality of life, This is agrees with study done in Tutkey[7] in which their results indicate that the mothers had higher scores than fathers on all distressed dimensions (somatization, anxiety and depression) because mothers are a nearest person with their children and spend more time with their children. there is a highly significant association between the age group of the caregivers and the physical domain of quality of life and significant association between age and psychological domain. it`s come along with study done in Thailand[3] which indicates that there is a highly significant association between the caregiver`s age of children with CHD and the QoL domains. there is a highly significant association between the marital status and QoL domains in social domain, and there is significant relationship between marital status and (physical domain) of QoL, This results agrees with study done in USA[15] they found that the marital quality have significant association with parental well-being of children with developmental disabilities. There is a highly significant association between socio-economic state and social domain of QoL, This finding similar with study done in Egypt[1],they found that there is a highly significant association between the financial situation of parent of children with CHD and social domain of QoL. There is a highly significant association between severity of congenital heart disease and (physical domain) of caregivers QoL, additionally the significant association were found between severity of congenital heart disease and psychological and social domains of caregivers QoL. This is

agreed with study done in Thailand[3], who found that the severity of congenital heart disease was associated with the caregiver burden experienced by the caregivers of children with congenital heart disease with statistical significance at $p < 0.05$.

CONCLUSIONS:

Most of the caregivers were mothers and housewives, their age groups were between (26-35) years old, were from urban areas, have ≤ 3 years of formal education and from low socio-economical level. The study shows that the majority of the caregivers stated their QOL rate as poor. And the majority of caregivers were suffering in (physical, psychological, social and spiritual) domains. There is a high significant association between the physical domains of QOL and the caregivers age and Severity of disease. a high significant association between the social domains of QOL of the caregivers their marital status, socio-economic level, lose of job and residential area) and Severity of Congenital Heart Disease of the Child's. also a significant association between the spiritual domains of QOL of the caregivers and their occupation.

RECOMMENDATION:

The study recommended to:

1. Implementation of an educational program for those caregivers of children with CHD.
2. Establish psychological care unit which consists of (Psychiatrist, psychologist, sociologist and nurse) in the surgical specialty hospital/Erbil cardiac center to consult and support the family of children with CHD.
3. Using mass media, TV and radio, lectures in different community associations or in health centers regarding risk factor, prevention of CHD and home care for child with CHD.

REFERENCES

1-Arafa A, Zaher R, A El-Dowaty A, Moneeb E and Dalia E. (2008). Quality of Life among Parents of Children with Children Heart Diseases. Health Quality Life Outcomes. Study Alexandria University ,Alexandria,Egypt [online] .Vol.6(91).Availablefrom.http://www. pubmedcentral.nih.gov/.(Accessed on 3- February-2010).

2-Marilyn J.Hockenbenberry and Wilson.2005. Wong`s Essential of Pediatric Nursing.7th Edition .New York.Elsevier.p.894.

3-Dhiranathara N. (2008).Factors Influencing Burden Experience by Caregivers of Childrenwith CongenitalHeartDisease. (M.Sc.Thesis).Mahidol University .Thailand . [Online].Available from.http:// www. mulinet10 .li.mahidol .a c. the/. (Accessed on 5-February-2010).

4-Speer K. (1999).Pediatric Care Planning 3rd Edition. New York. Spring house . pp17-82.

5-Stonge M and Lavoie F. (1997). The Experience of Caregiving Among Mothers of Adults Suffering from Psychotic Disorders: Factors Associated with Their Psychological Distress. Springerlink. [Online].Available from. http :// www. springer link.com/. (Accessed on 13- January -2010).

6-TheWHOQoLGroup (1998).The World Health Organization Quality of Life Assessment(WHOQoL): Development and general psychometric properties. Social Science and Medicine, 46, 1569-1585.avilable from: http:// www. psychiatry. unim elb.edu (Accessed on 10-December-2009).

7-Yildiz A, Celebioglu A and Olgun H. (2005). Distress levels in Turkish parents of children with congenital heart disease.Aust J Adv Nurs. M.Sc.Thesis. Atatürk University, Turkey [online].Vol.26 (3): [39-46].

Available from. http ://www .ajan. com.(Accessed on 3-August-2010).

8-Goldbeck L and Melches J. (2006).The Impact of the Severity of Disease and Social Disadvantage on Quality of Life in Families with Congenital Cardiac Disease. Journals of Cambridge.(Ph.D.Thesis).University Clinic for Child and Adolescent Psychiatry/Psychotherapy Ulm, Germany. [online].Vol.16(1);[67-73].Available from. http:// www. Journals.cambridge. org/.(Accessed on 30-Juley-2010).

9- Bacon L. (2010) .Children Have a Negative Impact on Physical Activity among Individuals with Heart Disease. Daily Science. Concordia University.Canada .[online].Availablefrom. http://www. sciencedaily. com/ .(Accessed on 22-Juley-2010).

10- Heart Disease Health Center.(2005). Heart Disease and Caregiver Burnout. Medical dictionary.[online].Available from. http:// www.webmd .com /heart-disease/ Caregiver Burnout .(Accessed on 3-Augest-2010).

11- Marino B, Tomlinson R and Drotar D *etal*, (2009). Quality of Life Concerns Differs among Patients, Parents, and Medical Providers in Children and Adolescents with Congenital and Acquired Heart Disease. Sickkid American Academy of Pediatrics., Department of Pediatrics, 13-13-Children's Hospital of Philadelphia, Pennsylvania USA..[online]. Vol.123 (4).[708-15]Available from. http: //www. aboutkids health . ca/News/ Default .aspx .(Accessed on 22-Juley-2010).

12-Van den Tweel W., Hatzmann J, Ensink S, van der Lee H, Peters M and Fijnvandraat K.(2008). Quality of Life of Female Caregivers of Children with Sickle Cell Disease. Ferrata Storti Foundation.Study.Academic Medical Center, Amsterdam, the Netherlands. [online].Vol.93(4);[588-93]. Available from. http://www. haematologica.org/ cgi/content/full/.(Accessed on 30-Juley-2010).

13-Hunfeld A,Temples A,Passchier J,Hazebroek W..and Tibboel D.(1999). Parental Burden and Grief One Years after the Birth of a Child with Congenital Anomaly. *J Pediatr Psychol Study*. Erasmus Univercsity. Netherland.(Abstract).[online].Vol.24 (6); [515] . Available from. http:// www. Jpepsy. oxfordjournals.org/cgi/ content /abstract/24/6/515 .(Accessed on 22-Juley-2010).

14-Dhiranathara N. (2008).Factors Influencing Burden Experience by Caregivers of Children with Congenital Heart Disease .M.Sc. thesis. Mahidol University.Thailand.[Online].Availabl e from. http:// www. mulinet10 .li. mahidol .ac.th /. (Accessed on 5-February-2010).

15-Evalotte M, Lundh U and Ethel F.(2002). Parental Stress in Relation to the Severity of Congenital Heart Disease in the Offspring. Pediatric Nursing. Nancy, France. [online] .Vol .28 (1);[28-33].Available from. http:// www. cat.inist. (Accessed on 30-Juley-2010).

16-Kersh J, Hedvat T, Hauser-Cram P. and Warfield M.(2006). The Contribution of Marital Quality to the Well-being of Parents of Children with Developmental Disabilities . Brandeis University, USA. PubMed. (abstract). [online]. Vol50 (12); [883-93].Availablefrom. http://www.ncbi. nlm.nih.gov/.(Accessed on 3-August-2010).