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Original Research Paper

Quality of Life of Mothers Having Children with Chronic Renal Failure

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ABSTRACT:

Background: During the last several decades, significant improvements had been achieved in management of children suffering from end stage chronic kidney disease (ESCKD), with advancements in dialysis care whether in predialysis period or dialysis technology which lead to prolong long-term survival of affected children. But these medical achievements saddle families (especially mothers) of ESCKD children with significant psychosocial, social, environmental and physical burdens. **Aims of study:** To assess the overall Health Related QoL among mothers of ESCKD children in Child Protection Teaching Hospital in Baghdad. To find out the association of socio-demographic and socio-economic variables with physical, psychological, social and environmental domains of QoL. **Methods:** A descriptive cross sectional study was conducted on a sample of 108 mothers of less than 16 years old children diagnosed with ESCKD attending hemodialysis unite in Child Protection Teaching Hospital in Baghdad during the 1st half of 2019.Mothers` health-related quality of life was assessed using World Health Organization – Health Related QoL BREF questionnaire. Chi-square test was used to find out significance of associations between related variables where P. value <0.05was considered statistically significant. **Results:** Social relationships Health Related QoL is the most impaired domain in studied mothers (43.8/100), while the least affected domain is the physical health (52.2/100). **Conclusion:** physical health quality of life of Mothers who were caring for children with ESRD on hemodialysis was affected but to lesser extent than other QoL domains, while social relationships was the most affected domain followed by psychological wellbeing then environmental domains.

Key wards: Quality of life, end stage renal failure, Baghdad.

INTRODUCTION:

Regarding care in the management of various chronic illnesses in children and adolescents indicate that it is the mothers who are the main people involved in the care process (1). Important assertions depend on this fact, such as the burden of the mothers who are the caregivers, who in addition to domestic responsibilities undertake complex activities which are not part of their routine, arising from the care for their children with chronic illnesses. Caregiver burden can culminate in acute and chronic physical disorders, resulting in isolation and depression, as well as financial disequilibrium, reduction in libido and self-accusation (2). The caregiver's burden is defined as objective when it corresponds to the physical and/or mental effects arising from the act of caring; and as subjective when related to the negative sensation which the act of caring provokes in the caregiver (3). The conceptualization and measurement of quality of life (QoL) in the early days, followed later by health-related quality of life (HRQoL) has been of interest to researchers from the fields of sociology and healthcare for several decades now. Increasingly, HRQoL is seen as a measurable outcome of healthcare (4). Providing round-the-clock care for a kid is only part of being a parent. When it comes to a kid with a chronic illness who will be dependent for the rest of his or her life, the nature and significance of this care shift dramatically. Taking care of these kids has a ripple effect on the whole family, especially the parents, lowering their quality of life and affecting their physical and emotional health (QoL). When a parent's own physical or mental health prevents them from providing the care and support a kid needs, that youngster is more likely to fall short of his or her full potential in terms of functioning and independence. How parents manage stress, build resilience, and deal with novel circumstances all have a role in how well their children do in their care. It has been shown via research that a parent's mental health declines the more

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time they spend with their impaired kid, especially if that parent is the mother (5). Unlike in adult patients, Childhood Chronic Kidney Disease CKD presents clinical features that are specific and totally peculiar to the pediatric age, such as the impact of the disease on growth. This impact is often under-recognized but should not be neglected. Moreover, Chronic Kidney Disease (CKD) has a great psychosocial impact, both on the patient and his family. The parents not only have to fulfill the role of parents, but also take on many tasks we normally associate with nurses and doctors. Therefore, we must be aware that the increasing survival of pediatric patients with CKD, due to the improvement in the clinical and therapeutic management, will lead to a large number of effects on HRQoL mainly that of mothers. In Iraq, there is a strong emotional relationship between family members. Parents are directly affected by the whole family and have a special commitment towards their children. This traditional structure is an important source of support for the diseased children. Unfortunately, in the context of health care in Iraq, the needs and problems of family caregivers have not been addressed effectively and they don't receive appropriate support. The concept of care is a process of taking care activities and its associated responsibilities (6). In addition to physical pressure, caring a chronically diseased child by his mother as a care giver bears all features for the chronic stress since it is associated with high levels of unpredictability and uncontrollability. These factors cause the secondary stress in different aspects of life, including work and family relationships. Stress-making factors to which caregivers are exposed result in mental stress and disorder in health behaviors, which in turn stimulate physiological responses, illness and even death (7). The term 'caregiver' refers to those who, during the treatment procedure, are mostly involved in looking after the patient and help the patient to handle and adopt with that chronic disease (8). Caregivers are vital and national source of health care and families (especially mothers) are often the first source of home health care.

Aims of study

1. To assess the overall HR QoL of mothers of children with chronic renal failure on hemodialysis
2. To find out the association between socio-demographic and socio-economic variables (e.g. age, gender, education, occupation, residency, marital status) and physical, psychological, social, and environmental domains.

METHODS:

Study design and duration of data collection

A descriptive cross-sectional study. Data collection was carried out during the period from 1st of April to 30th of June 2019; during the working hours of the hemodialysis unite Child Protection Teaching Hospital Medical City

Study Setting

The study was conducted in hemodialysis unit at Child Protection Teaching Hospital Medical City, Baghdad. This unite offers services to people lived everywhere in Baghdad, mainly in Al-Russafa district and the rural areas around.

Study population and sampling procedure

All mothers of children with ESCKD attending Child Protection Teaching Hospital Medical City for hemodialysis for their children were included.

Tools of data collection

Data was collected by using self-administered questionnaire consisted of two parts

Part one

This part ask about demographic information of patients: gender , age and duration of hemodialysis of ESCKD child, while each mother was asked to mention her age, educational level, her and her husband occupation, house and car property, Marital status, and residence.

Part Two

The researcher employed the Arabic version of WHOQOL-BREF, a shorter version of WHOQOL 100 survey tool, which was developed by the WHO to capture the broad aspects of HRQOL. There are a total of 24 satisfaction items in the WHOQOL-BREF questionnaire, split between four categories: physical health (DOM1), mental health (DOM2), social relationships (DOM3), and environmental health (DOM8). The questionnaire includes two items measuring both overall quality of life and general health (DOM4). This instrument emphasizes the subjective responses of person rather than their objective life conditions, with assessment made over the preceding two weeks. It was developed in a wide range of languages in different cultural settings and yields comparable scores across cultures **(9)**. The scale includes 5-point Likert response ranging from 1 (very dissatisfied/very poor) to 5 (very satisfied/very good). The scores for each domain are scaled in a positive direction, that is, a higher score indicates a higher QOL rating **(9)**. The scale was prepared so as to be filled by the individual. Scoring of domains was carried out according to WHOQOL user manual (10), where domain scores are scaled in a positive direction with 3 questions in negative direction. A score of mean ± SD on each domain is considered fair, a score of < mean-1 SD is poor and a score of > +1SD is good. (11,12) The dependent variable for this study was the quality of life of studied mothers, while the independent variables of this study included: child age, child gender duration of HD, mother age, residence and SES. The socioeconomic status (SES) was calculated using Wali Omer and Tariq Al-Hadithi method (13). SES= Education + Occupation + House ownership*1 + Car ownership0.5 + [(AGE-20)/100] - retired/unemployed

Ethical approval and permission

1. Permissions obtained from Ministry of Health by official letters directed to the authorities of Children Care Hospital.
2. Conduction of the study had been approved by the ethical committee at Iraqi Council of Medical Specializations.
3. The mothers of patients gave informed consent to participate after the objectives of the study were explained to them.

Statistical analysis

The data were entered into Microsoft Excel. Then they were loaded into Statistical Package for Social Sciences (SPSS) software (version 23). For descriptive analysis categorical variables were presented as frequencies and percentages. Continuous variables were presented as (Means ± SD). Pearson Chi square test has been used to examine the effects of socio-demographic data on the domains of parents' QoL.

P-value level of < 0.05 was considered for significant association.

RESULTS:

One hundred and eight mothers of children with ESCKD met the criteria to be included in this study.Sixty-three (58.3%) of CKD children were males, the mean age of children was 10±1.5 years, 55(50.9%) aged less than 10 years, the duration of hemodialysis was equal or less than 1 year in 61(56.5%), 48(44.4%) of children had severe complicated form of ESCKD, Characteristics of diseased children , the mean age of mothers was 38±4.12 years, 63 (58.3%) of them aged less than 40 years, 80(74.1%) lived in urban areas. Regarding the socioeconomic status of studied mothers; 28(25.9%), 39(36.1%), 25(23.1%) and 16(14.8%) related to poor, fair, good and excellent socioeconomic state levels respectively,as in table 1.

Table 1 General characteristics of studied subjects

		No.(total 108)	%
Child gender	Male	63	58.3
	Female	45	41.7
Child age	Mean ±SD	10±1.5 years	
Child age	≤10 years	55	50.9
	>10 years	53	49.1
Duration of HD	≤1 year	61	56.5
	>1 year	47	43.5
Disease severity	Severs	48	44.4
	less severe	60	55.6
Mother age	Mean ±SD	38±5.12 years	
Mother age	< 40 years	63	58.3
	≥40 years	45	41.7
Residence	Urban	80	74.1
	Rural	28	25.9
Socioeconomic status	Poor	28	25.9
	Fair	39	36.1
	Good	25	23.1
	Excellent	16	14.8

Table 2 shows the QoL domain scores were lowest in social health (43.8±9.2) and the highest in physical health (52.2±11.4).

Table 2 distribution of studied mothers according to mean scores of QoL domains

	Mean	Std. Deviation
Physical health	52.2	11.4
Psychological wellbeing	44.8	10.5
Social relationships	43.8	9.2
Environmental health	49.3	12.3

Regarding impression of study subjects about GQOL (general quality of life), 27% had poor, 45% fair and 28% had good impression. Gender was the only variable to be significantly associated with GQOL (Pv= 0.028). As in figure 1 and table 3

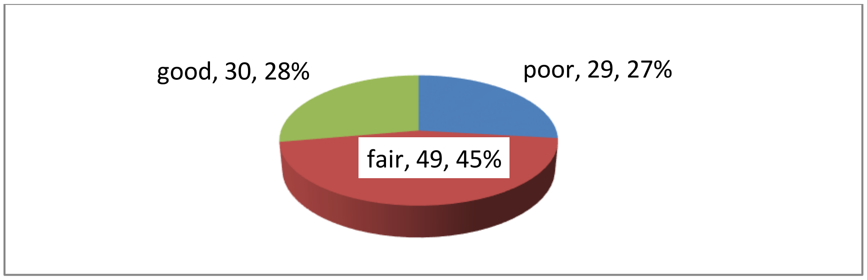

Figure1: Distribution of studied sample according to GQOL

Table 3 association between studied variables and patients` perception regarding their general QOL

		Total N= 108		**Poor N= 29**		**Fair N= 49**		**Good N=30**		**P value**
		N	**C %**	**N**	**R%**	**N**	**R%**	**N**	**R%**	
Child gender	**Male**	63	58.3	23	36.5	25	39.7	15	23.8	0.028
	Female	45	41.7	6	13.3	24	45	15	33.3	
Child age groups	**≤10 y**	55	50.9	15	27.3	26	47.3	14	25.5	0.854
	>10 y	53	49.1	14	26.4	23	43.4	16	30.2	
Duration of HD	**≤1 y**	61	56.5	18	29.5	28	45.9	15	24.6	0.641
	>1 y	47	43.5	11	23.4	21	44.7	15	31.9	
Disease severity	**Severs**	48	44.4	10	20.8	22	45.8	16	33.3	0.345
	Less sev.	60	55.6	19	31.7	27	45	14	23.3	
Mother age	**< 40 y**	63	58.3	17	27	28	44.4	18	28.6	0.969
	≥40 y	45	41.7	12	26.7	21	46.7	12	26.7	
Residence	**Urban**	80	74.1	20	25	35	43.8	25	31.3	0.384
	Rural	28	25.9	9	32.1	14	50	5	17.9	
SES	**Poor**	28	25.9	9	32.1	13	46.4	6	21.4	0.758
	Fair	39	36.1	10	25.6	15	38.5	14	35.9	
	Good	25	23.1	7	28	13	52	5	20	
	Excellent	16	14.8	3	18.8	8	50	5	31.3	

In relation to GH, 25% of mothers had poor, 44% fair and 31% had got good perception. SES had been shown to have significant association with general health of the participating subjects (P value= 0.001). As in figure 2 and table 4.

Table 4 Association between studied variables and patients` perception regarding their general health

		Total N=108		Poor N= 27		Fair N=48		Good N=33		P value
		N	%	N	%	N	%	N	%	
Child gender	**Male**	63	58.3	15	23.8	30	47.6	18	28.6	0.732
	Female	45	41.7	12	26.7	18	40	15	33.3	
Child age groups	**≤10 y**	55	50.9	14	25.5	29	52.7	12	21.8	0.103
	>10 y	53	49.1	13	24.5	19	35.8	21	39.6	
Duration of HD	**≤1 y**	61	56.5	15	24.6	28	45.9	18	29.5	0.939
	>1 y	47	43.5	12	25.5	20	42.6	15	31.9	
Disease severity	**Severs**	48	44.4	11	22.9	21	43.8	16	33.3	0.828
	less sev.	60	55.6	16	26.7	27	45	17	28.3	
Mother age	**< 40 y**	63	58.3	15	23.8	31	49.2	17	26.9	0.475
	≥40 y	45	41.7	12	26.7	17	37.8	16	35.5	
Residence	**Urban**	80	74.1	23	28.75	35	43.75	22	27.5	0.258
	Rural	28	25.9	4	14.3	13	46.4	11	39.3	
SES	**Poor**	28	25.9	11	39.3	15	53.6	2	7.1	0.001
	Fair	39	36.1	8	20.5	21	53.8	10	25.6	
	Good	25	23.1	7	28	8	32	10	40	
	Excellent	16	14.8	1	6.3	4	25	11	68.8	

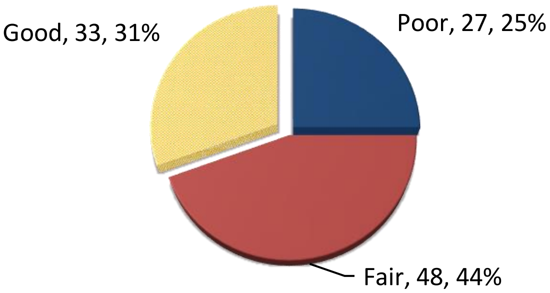

Figure 2: Distribution of studied sample according to GH

Regarding physical health figure 3 showed that 34(32.5%), 27(25%) and 47(43.5%) mothers presented with poor, fair and good physical health respectively.

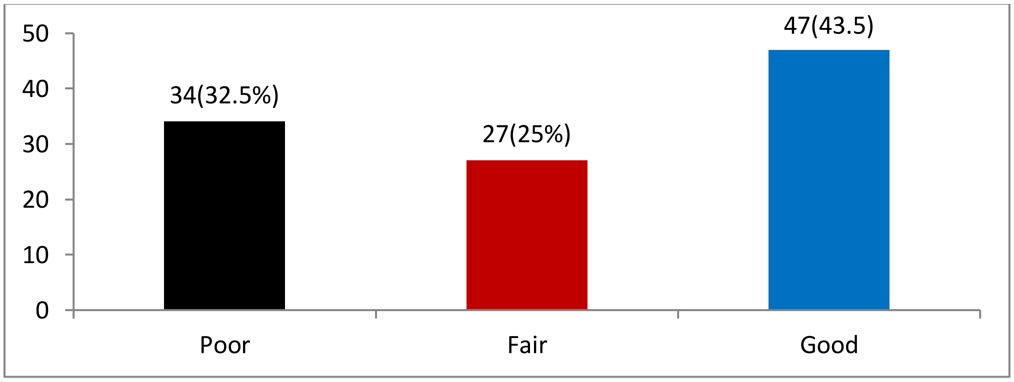

Figure 3: Distribution of studied subjects according to physical health

Regarding psychological wellbeing: figure 4 showed that 37(34.3%), 49(45.4%) and 22 (20.3%) patients presented with poor, fair and good psychological wellbeing respectively.

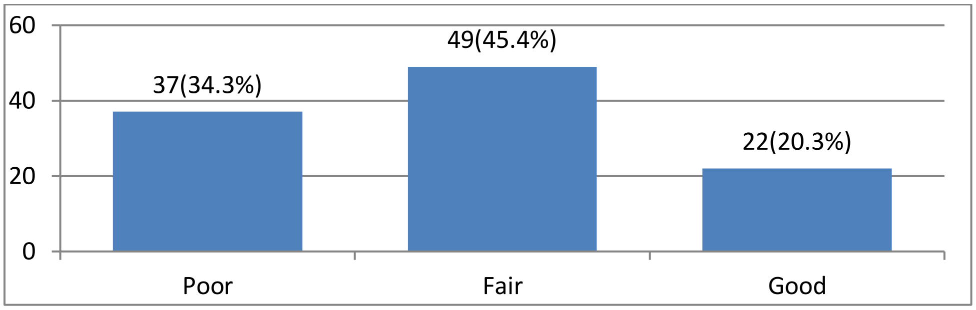

Figure 4 Distribution of studied subjects according to psychological wellbeing

Regarding social relationships figure 5 showed that 34(31.5%), 40 (37%) and 34 (31.5%) mothers presented with poor, fair and good social relationships respectively.

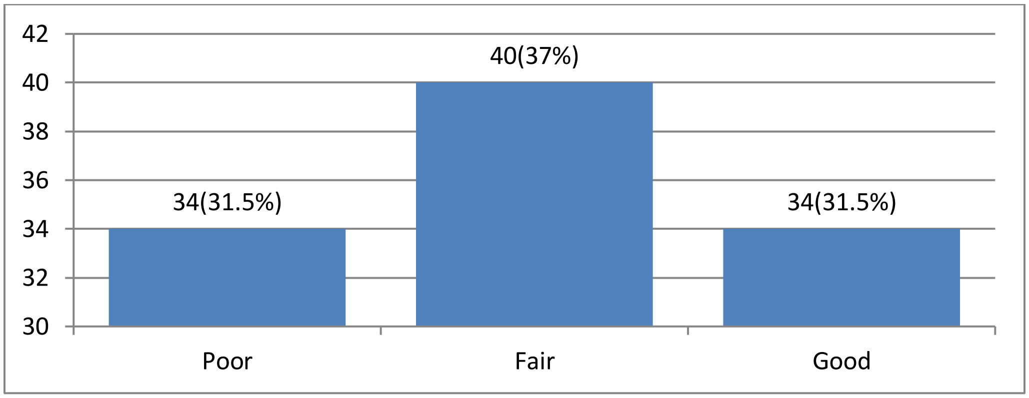

Figure 5: Distribution of studied subjects according to social relationships

Figure 6 showed that 30(27.8%), 43(39.8%) and 35 (32.4%) patients presented with poor, fair and good environmental health status respectively.

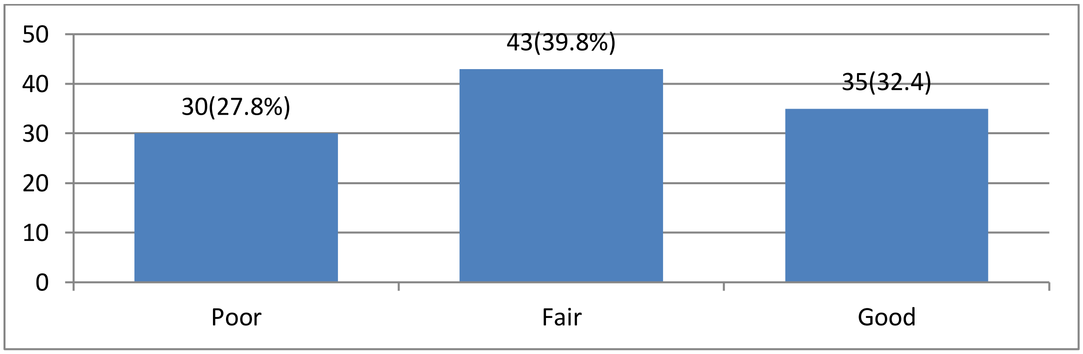

Figure 6 Distribution of studied subjects according to environmental health

DISCUSSION:

General health and QoL

The results of this study showed that studied mothers scored low general score according to both their personal rating and according to domains measured one where the score are less than 50/100 for both. These results agreed with results of other studies discussing association between low HRQL of parents and presence of chronically ill sons or daughters like that found by Benjak in Croatia during 2011 when the study concluded that parents of children with Autism reported a poor QoL and general health perception(14). Studies were done by Bih- Ching Shu 2009, Mugno 2007 and Yamada 2012 pointed similar results that poor QoL were recorded among parents of children suffered from chronic diseases (15-16)

Gender of the diseased child had no significant association with HRQOL of mothers in any studied domains and this result goes similar to Wicks results 1997, which reflects no gender discrimination in mothers` feeling towards their diseased child (14).

Social relationships

Mothers in this study recorded lowest scores in social domain with significant association between poor social relationships and younger age of affected child. Poor SES condition of the family was also associated with poor social relationships. This results goes in line with Allison Tong conclusion in 2008 that, parents lived with constant uncertainty about their child's medical prognosis and future prospects. At a time when their own support systems were being tested, parents were expected to manage the child's rigorous medical schedule, learn about the illness and its treatment, make travel and housing arrangements, budget for and stick to dietary restrictions, and keep up with household chores (15).

In some studies focusing on the QOL of caregivers of children with a chronic condition, the social domain was the most significant indicator of poor QOL. Caregivers often have significantly poorer social relationships compared with parents of healthy children (17).

Psychological wellbeing

The second affected QoL domain was psychological wellbeing with significant association between poor psychological wellbeing and younger child age, older mother age and lower SES status. These results were also pointed by Fernanda Stella and co researchers 2014(18), when they found that the need for hemodialysis not only causes a challenging routine for mothers, but intense distress for having to live with the existence of the machine. With the need for hemodialysis, an unknown reality brings about instant change to their lives. The outcome of this study is also similar to the results of Freidman in 2006 who stated that "amongst caregivers of children on peritoneal dialysis, the prevalence of depression was higher than that in a control group of parents with healthy children. More striking is the fact that only 56% of these caregivers were aware of their tendency toward depression. Parents tend to report being less healthy overall if one of their children is unwell, and this correlation increases with the severity of the child's illness (19). This study's findings corroborated those of Wiedebusch et al., who found that parents of children with CKD experience significant psychological distress, poor quality of life, and depression while their kid is on dialysis (20) Findings from this research corroborated the findings of Richard Schulz (2008), who found that the physical and mental health of family care grievers was more negatively impacted when the care receiver suffered from acute pain or a worsening condition, even for mothers (21).

Environmental health

The third affected QoL domain is the environmental one with significant association between poor environmental condition and poor SES status, younger child age and older mother age, the explanation of that association may be related to low socioecomic status of mother families in general which the same explanation adopted by Dardas 2014 in his study about Jordanian parents of children with autistic disorder (22). Medway et al inform this understanding by exploring the role of financial stress in relation to a parent’s ability to care for a child with CKD (23).

Physical health

The least mothers` QoL domain affected by being care givers to their ESCKD children is the physical health, although this study showed significant association between older age female and poor physical health but this association could be attributed to the effect of age on physical health, another significant association was noticed between poor SES and poor physical health, which may reflect that shortage of money may prevent mothers from looking after their children and their own health. Regarding association between physical health and care giver burden , Martin Pinquat and Silvia Sarensen 2003, concluded that differences in the levels of physical health among caregiver in favor of noncaregivers were statistically significant, but small (24). The low effects on physical health of mothers in comparison with social relationships and psychological well-being in this study is consistent with Richard Schulz, and Paula R. Sherwood in 2008 conclusion, that The detrimental physical effects of caregiving are generally less intensive than the psychological effects, regardless of whether they are assessed by global self-report instruments or physiologic measures such as stress hormone levels(20).

Limitations of this study

1. The major limitations of this study are the one center based sample in that it may not be representative of patients with ESCKD throughout Baghdad city, although it is the main center in the medical city which is the biggest medical campus in Iraq
2. There are no previous studies on QOL of mothers of children with ESCKD using the (WHOQOLBREEF) in Iraq, direct comparison with other studies is difficult.

CONCLUSION:

This study showed that,

the physical health quality of life of Mothers who were caring for children with ESRD on hemodialysis was affected but to lesser extent than other QoL domains, while social relationships was the most affected domain followed by psychological wellbeing then environmental domains.

Recommendation

1. Planning and implementing education programs for mothers of children with ESRD.
2. Involvement of family members of children with ESRD in responsibility for care of those children.
3. Further studies on this topic in other governorates in Iraq are necessary.
4. Increase the number of specialized centers for HD, and improve the quality of services in order to decrease the responsibilities and financial burden on the patient.
5. More researches are needed to identify the prevalence of disease in Iraq.

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