Quality of Life of AdolescentsReceiving Hemodialysis Therapy in Baghdad Teaching hospitals

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Abstract:

Objective(s): The present study aims to: (1) identify adolescents' QOL who receive hemodialysistherapy, (2) determine the impact of hemodialysis on adolescents' QOL, and (3) find out the relationship between QOL of adolescents who receive hemodialysis therapy and their sociodemographic characteristics.

Methodology: A descriptive study was conducted on adolescentsof both genderswho experience chronic renal failure and receiving hemodialysis therapy, and their age range between 10 years to 19 years. The study started from the period of September2nd,2016 to May 22^{nd} ,2017. The present study was carried out at the dialysis centers in Baghdad Teaching Hospitals. A non-probability (purposive) sample of (50) patients who have been attending at Hemodialysis units.

For the purpose of study, questionnaire format was designed and constructed by the investigator depending on:1. Adopted and developed quality of life scale from the world health organization scale (WHOQOL), to measure the variables underlying the present study, 2. Review of available literature related to the concept of QOL, burden of disease, and treatment upon adolescents with Hemodialysis, 3. Meeting with adolescents on Hemodialysis were carried out and open-ended questions used related to their disease and how it effects on their daily living activities, 4.

The researcher experiences in the field work in dialysis centers. The study instrument consists of two parts:

Part I: Adolescents Demographic Characteristicsinclude three sections:

section 1: Adolescents Demographic Data,

Section 2:Disease Related Information and Section 3: Socio-economic status scale(SESS).Part 2: Quality of Life Measurement Scale.Validity and reliability

of the instrument is determined through pilot study. Data collection is initiated from December 22^{nd} , 2016 to March 2^{nd} , 2017 took approximately nine weeks. Data are analyzed through the use of SPSS (Statistical package for Social Sciences) version 20.0 application Statistical analysis system and Excel application. Descriptive and inferential statistical data analysis approaches are employed

Results:Results of data analysis depict that participants instudy sample demonstrated that the majority of adolescents with hemodialysis therapy have decline in quality of life concerning the physical, psychological, social and level of independence domains at moderate level.

Conclusion:The study concludes hemodialysis has an impact on the different psychological, social, level of dependent and physical life aspects of adolescents, also those adolescents' disease information and socioeconomic status have contributed to the creation of psychological, social, physical and level of dependent that generate effect on adolescents' quality of life withvarious levels.

Recommendations: the researcher recommended the following: 1. Advances in medical care resulted in minimize disease burden and increased long-term survival of adolescent patients with chronic kidney disease (CKD) subsequently optimizing QOL .2. The importance of evaluating behavioral and social repercussions of CKD (Psychosocial interventions) in order to improve the life quality and stimulate coping strategies to give adolescent the capacity and confidence to manage, and gradually take responsibility for, their own health, as well as progressing in their studies and participating in the wider community. Since more adolescent with chronic kidney disease are reaching adult age, so requires attention to the psychosocial and developmental factors to ensure successful transition to adulthood.

3.Ongoing education for patients and distribution asimple manual booklet and is necessary to enhance their knowledge about the illness, understand the impact of the disease and its treatment on their lives.4. Continuous educational program for health team to increase knowledge and skills about the importance of improving QOL of HD patients through improving quality of care and health education for patients. 5. Future studies with a larger sample from different centers and more geographically diverse locations are needed.6. Health oriented mass media approach should be employed by the Ministry of Health to increase population Knowledge and awareness about the renal failure disease.

Key words: Hemodialysis, Quality of life, Adolescents

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I. Introduction

Hemodialysis is a therapy for kidney failure that usage a machine called a dialyzer to filter patient's blood outside his body. This procedure can replace part of kidney task. but is not a cure for kidney failure; however, it can help patient sense better and live longer⁽¹⁾. Hemodialysis can only replace a very small part (15%) of what normal kidneys do. If patient do not get enough dialysis, his body will retain the waste products and extra fluid that cause sick and feel tired⁽²⁾. Dialysis patient are at hazard for contracting blood-borne contamination, including hepatitis viruses (HBV and HCV): viral hepatitis among dialysis patients is linked with significant severity and bad prognosis for both HBV and HCV (3). Chronic kidney disease (CKD) is emerging as an important problem worldwide. However, data on the burden of CKD in the Arab world remains poorly understood ⁽⁴⁾. Kidney disease is the 9th leading cause of death in the United States. Every year, kidney disease kills more people than breast or prostate cancer $^{(5)}$. In Iraq, In the last years the hemodialysis patients increased⁽⁶⁾.Mortality rate for children with ESRD receiving dialysis therapy is between 30 and 150 times that of the general pediatric population. Actually, the anticipated remaining lifetime for a child 0-14 years of age and on dialysis is only 20 years⁽⁷⁾. CKD is a massive social and economic problem in addition to medical problems, the management policy should be changed from therapy to prevention. Since the cost of dialysis and kidney transplantation is increasing over time⁽⁸⁾. Goals of referred adolescent to receive hemodialysis therapy involve anticipation and replacement of lost physiologic functions so that the adolescent enable grow and develop normally ⁽⁹⁾. Chronic kidney failure (CKF) causes changes in habits and provokes emotional changes in children and adolescents from the moment of diagnosis and beginning of living with the disease, these changes may evident through feelings of insecurity and fear, in addition to limitations on quality of life (QOL), leading to a higher incidence of psychological changes than in the general population. The changes affecting children and adolescents modify their perceptions of life, as well as CKI trigger stress, disrupt their lives, affect their selfimage ⁽¹⁰⁾. The QOL is not a new notion, numerous sciences such as sociology, psychology, and economics have been used it. The term QOL imply to the physical, psychological, and the social domains of health, seen as prominent areas that that are affected by the persons experiences, beliefs , expectations, and perceptions. The term quality implies the grade of excellence of characteristics, different people may value different areas of life, and therefore QOL means different thing to different people (11). Health-related quality of life (HRQOL)in children with end-stage renal disease (ESRD), is a valid and important clinical measure for monitoring the child's well-being and functional condition. HRQOL is an important clinical measure of the effects of disease and of the beneficial effects of medical treatment for children undergoing hemodialysis (HD) (12). Throughout the previous decade, there has been increased focus internationally on measuring the client perspective when evaluating the burden of disease benefit of treatment, self -assessment of QOL rating what people are able to make and how they feel $^{(13)}$.

II. Methodology

A descriptive study design was conducted on adolescent boys and girls having chronic renal failure and receiving hemodialysis therapy and their age range between 10 years to 19 years. The study started from the period of September 2nd, 2016 to May 22nd, 2017. The present study is carried out at thedialysis centers in Baghdad Teaching Hospitals. A non-probability (purposive) sample of (50) patients who have been attending at hemodialysis units.For the purpose of study, questionnaire format, was designed and constructed by the investigator depending on:1. Adopted and developed quality of life scale from the world health organization scale (WHOQOL), to measure the variables underlying the present study, 2. Review of available literature and studies related to the concept of QOL and burden of disease and treatment upon adolescents with Hemodialysis, 3. Meeting with adolescents on Hemodialysis were carried out and open-ended questions used related to their disease and how it effects on their daily living activities, and 4. The researcher experiences in the field work in dialysis centers. The study instrument consists of two parts: Part I: Adolescents' patient Demographic Characteristicsinclude three sections: section 1: Adolescents Demographic Data, Section 2: Disease Related Information and Section 3: Socio-economic status scale(SESS).Part 2: Quality of Life Measurement Scale.Validity and reliability of the instrument is determined through pilot study. Data collection is initiated from December 22nd, 2016 to March 5th,2017 took approximately nine weeks. Data were analyzed through the use of SPSS (Statistical package for Social Sciences) version 20.0 application Statistical analysis system and Excel application. Descriptive and inferential statistical data analysis approaches are employed.

Variables		Frequency	Percent
		Frequency	Tercent
	10-14 years	22	44.0
Ages (years)	15-16 years	16	32.0
Ages (years)	17-19 years	12	24.0
	Total	50	100.0
	Male	22	44.0
Gender	Female	28	56.0
	Total	50	100.0
	Rural	21	42
Resident	Urban	29	58
	Total	50	100.0
	Full time Student	6	12.0
	Student and working	-	-
Employment status	Working	6	12.0
	Do not work	38	76
	Total	50	100.0
	Illiterate	19	38.0
	Read and write	12	24.0
Educational level	primary school	4	8.0
	intermediate school	11	22.0
	secondary school	4	8.0
	Total	50	100.0
Socioeconomic status score	High	7	14.0
	Moderate	12	24.0
	Low	31	62.0
	Total	50	100.0

III. Results
Fable (1) Distribution of the Study Sample by their General Information

Table (1) demonstrates table shows that 44% of the study sample their age between (10-14)years, 56% of them were female, 58% of adolescents from urban, 76% of them were do not work, 38% were illiterate and 62% of them from low level of socio economic status score.

Table (2):Distribution	of the Study Sample by	their Information a	about disease

Variables		Frequency	Percent
	Cysts above kidneys	1	2.0
	cancer cells	-	-
	Glomerulonephritis	1	2.0
Causes of renal failure	One kidneys	7	14.0
	Deformity in Urinary system	13	26.0
	Another cause unmentioned	28	56.0
	Total	50	100
	Less than 1 year	12	24.0
	1-2years	15	30.0
Duration of Hemodialysis therapy	2-3years	15	30.0
	More than 3 years	8	16.0
	Total	50	100
	2 sessions/week	26	52.0
Frequency of Hemodialysis therapy	3 sessions/week	21	42.0
during week	Another	3	6.0
	Total	50	100
	Hypertension ↑ or↓	16	32.0
Complication during Hemodialysis	Nausea/ Vomiting	1	2.0
	Pain	3	6.0
	Headache	2	4.0
	Another	7	14.0
	Hypertension \uparrow or \downarrow , bleeding and headache	1	2.0
	Hypertension ↑ or↓, Nausea/ Vomiting and headache	2	4.0
	Hypertension ↑ or↓ and headache	5	10.0
	Hypertension ↑ or↓ and other	1	2.0

Variables		Frequency	Percent
	bleeding and headache	1	2.0
	Bleeding and other	2	4.0
	Nausea/ Vomiting and headache	3	6.0
	Nausea and other/ Vomiting	2	4.0
	Pain and headache	1	2.0
	Pain and other	3	6.0
	Total	50	100
	Yes	17	34.0
Are patient follow diet	No	33	66.0
	Total	50	100
Another comorbid chronic diseases in addition to renal failure	Heart disease	9	18.0
	Bone and joint disease	12	24.0
	D.M	4	8.0
	H.T	-	-
	Another disease unmentioned	18	36.0
	No diseases	7	14.0
	Total	50	100
Family history of disease (any relative	Yes	17	34.0
has renal failure)	No	33	66.0
	Total	50	100
Degree of relative	1st degree	17	100
	2nd degree	-	-
	3rd degree	-	-
	Total	17	100

Table (2):(Continued)

Table (2) reveals that 56% of adolescents has other causes of renal failure un mentioned in questionnaire format, the majority of patients has (1-2) and (2-3) years when beginning onset uses the hemodialysis therapy, 52% of patients has 2 sessions/week the time number of dialysis session per week, the majority of patients had Hypertension $\uparrow or \downarrow$ as complication during hemodialysis, 66% of them do not follow a dietary guide for patient with renal failure, 36% of them had another chronic diseases un mentioned and 34% of the adolescents had a relative renal failure from 1st degree.

List	Quality of life	Mean \pm S.D.	Assessment
1	Physical domain	1.98 ± 0.39	М
1-1	Fatigue	2.18 ± 0.54	М
1-2	Pain and discomfort	1.77 ± 0.38	М
1-3	Sleep and rest	1.94 ± 0.48	М
2	Psychological domain	2.15 ± 0.31	М
2-1	Body image and appearance	2.03 ± 0.52	М
2-2	Positive feeling	2.16 ± 0.37	М
2-3	Negative feeling	2.24 ± 0.44	М
2-4	Worry	2.15 ± 0.39	М
2-5	Self esteem	2.07 ± 0.48	М
2-6	Thinking, memory and concentration	2.26 ± 0.27	М
3	Level of dependence domain	2.24 ± 0.50	М
4	Social relationship domain	2.08 ± 0.42	М
4-1	Family and peer interaction	2.13 ± 0.40	М
4-2	Communication	2.07 ± 0.65	М

 Table (3): The Impact of Hemodialysis on Adolescents' Quality of Life

Std. Dev. (S.D.), level of assessment: (1-1.67) = Low;(1.68-2.33) = Moderate; (2.34-3.00) = High

Table (3) shows that, all domains and sub domains of quality of life were affected at moderate level by the hemodialysis therapy.

IV. Discussion

Table 1: The findings of the present study show that the majority of the study sample age groups (44 %) was within (10-14) years old. This result does not mean that the peak incidence age of chronic renal failure in adolescent was within (10-14)years, because the explore of the peak incidence age of kidney failure in this study was difficult, that because our study was a descriptive study conducted to clarify the concept of quality of life among hemodialysis patients,not to clarify the incidence age for those patients (Researcher opinion). Regarding to gender the findings indicate that the more than half study sample (56%) were female. Chronic

renal failure does not differentiate between the gender, but this might be because discrimination of our community in boys' preference on girls in getting kidney transplant so girls stay on hemodialysis therapy while boys gets kidney transplant (Researcher opinion). Throughout the course of the present study more than half of the study sample (56.0%) living at urban areas. This result might be because the capital cities or city centers always have availability of hemodialysis centers so possible the ratio of hemodialysis incidence in rural is high but they can't access to hemodialysis centers for many reason e.g.: transportation cost, safety status of country, time consumption, wrong belief... etc. The study results show that the majority of study subjects (76 %) were do not work as employment status. Its normal for people with chronic disease difficulty performance practice routine like work or school permanence especially those with long duration history of renal failure exceed two years or more whereas in nature those will face difficulty in care in his self (Researcher opinion). Concerning with educational levels, (38%) of study sample were illiterate. Person with chronic renal failure faces more difficulties in completing their education, in the other hand low parental level of education may result in a direct impact on their children's education. Finally, regarding the socioeconomic status the majority of study sample about (62%) were belonged to low socio-economic status. Logical in this study finding that majority of study sample belonged to low level of socio-economic status and if conversely parent of adolescent with hemodialysis patient might be able to do kidney transplant.

Table 2: Analysis of clinical characteristics revealed that the mostly (56%) causes of renal failure belong to other causes rather than causes listed in questionnaire for participate choice, the other causes may be one of the following:

Reflux nephropathy, Nephrotic syndrome, Nephritis, Decreased blood flow to the kidneys for a period of time, surgery, or shock. Regarding to the duration of disease (30%) for both (1-2 years) and (2-3years). Duration of dialysis plays an important role affecting QOL in dialysis patients. As duration of dialysis increases, QOL of dialysis patients deteriorates. According to the frequency of Hemodialysis session, most(52%) of study participants were at 2 sessions weekly and (42%) have 3 sessions weekly. Might be due to few dialysismachines available in our centers lead to decreasing hemodialysis session. Relative to total time consumed in dialysis centers per week the majority of the study sample (42%) were consume 6 hours per week in dialysis centers. This 6 hours indicate time of hemodialysis therapy session rather than time consume in traveling from house to dialysis centers and time consume in longer travel time was associated with lower QOL. Government of Iraq should provide dialysis unit and services of ESRD patients at all areas not only in cities to decrease effort and facilitate their life subsequently improve QOL. The finding of the present study revealed that the (32%) of study sample have hypertension as complication during Hemodialysis. Concerning with are patient fallow diet the majority of patient (66%) were not fallowing diet. In addition, the study results showed that the majority (36%) of study sample suffer from diseases associated with chronic kidney disease(Comorbid disease) did not remember in questionnaire format like (hepatitis, Spina bifida, etc...

Table 3:In general, the quality of life of adolescents with hemodialysis therapy in this study was impaired concerning the physical, psychological, social and level of independence. Concerning physical domain study results showed the effected of the physical domain by 3 indictors or sub domain under 3 levels scales of never, sometime and always. The physical domain and their sub domain had moderately affected in all sub domains (fatigue, pain and discomfort, sleep and rest). The present study findings revealed the effects of hemodialysis therapy on psychological domain which includes (6) indicators or sub domains under 3 levels scale of never, sometimes, and always. The psychological domain and their sub domain (body image and appearance, positive feeling, negative feeling, worry, self-esteem, thinking and memory and concentration) moderately affected by the disease in all aspects. The presence of chronic diseases during childhood and adolescence raises the risk of psychological disorders or psychological imbalances resulting not only from the illness but also from the treatment and difficulty living with the disease and altering renal function. These patients suffer from the fact that the illness affects not only their lives, but also those of their families. The level of independence domain result show that moderately affected by hemodialysis therapy which include one indicators or sub domains (daily living activity). Finally, according to study findings, the effects of hemodialysis therapy on social domain which include (2) indicators or sub domains (family and peer interaction, communication) was moderately affected. chronic disease is especially difficult for adolescents to handle because it creates stress in areas already problematic for this age group (Researcher opinion).

Conclusion:

According to the finding of the present study, the researcher concluded the following:

1. The finding of study indicated that the most of study sample was female with age group (10-14) years old. The majority of adolescent hemodialysis patients unemployed. The most of study sample were illiterate. The vast majority of them coming from family of low socioeconomic status.

- 2. Concerning the clinical characteristics, the most of hemodialysis patients were with duration of hemodialysis at (1-2) and(2-3) years, and two sessions weekly for frequency of hemodialysis session. The majority of study sample was with un known causes of renal failure, but hypertensive the most complication during hemodialysis therapy. The majority of study sample do not follow diet and with another comorbid diseasein addition to renal failure not mentioned in questionnaire like hepatitis, spina bifida...etc. Mostly of study sample with non-family history of disease.
- 3. The study sample demonstrated that the majority of adolescents with hemodialysis therapy have decline in quality of life concerning the physical, psychological, social and level of independence domains at moderate level.
- 4. Throughout the results of the present study the research hypothesis is accepted.

Recommendations

According to the conclusion of the present study, the researcher recommended the following:

- 1. Advances in medical care resulted in minimize disease burden and increased long-term survival of adolescent patients with chronic kidney disease (CKD) subsequently optimizing QOL.
- 2. The importance of evaluating behavioral and social repercussions of CKD (Psychosocial interventions) in order to improve the life quality and stimulate coping strategies to give adolescent the capacity and confidence to manage, and gradually take responsibility for, their own health, as well as progressing in their studies and participating in the wider community.
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- 3. Ongoing education for patients and distribution asimple manual booklet and is necessary to enhance their knowledge about the illness, understand the impact of the disease and its treatment on their lives.
- 4. Continuous educational program for health team to increase knowledge and skills about the importance of improving QOL of HD patients through improving quality of care and health education for patients.
- 5. Future studies with a larger sample from different centers and more geographically diverse locations are needed.
- 6. Health oriented mass media approach should be employed by the Ministry of Health to increase population Knowledge and awareness about the renal failure disease.

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