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Living with Dialysis. Elements to Improve the Quality of Life (QoL)

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<u>An Introduction to</u> <u>ATINER's Conference Paper Series</u>

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Abstract

Summary: Prevalence of chronic kidney disease is much higher among general population. According a study done in the U.S. was observed that in this country there are about 2.6 million people with chronicle kidney disease (2.3). The progress of these diseases goes towards the terminal stages and this is a moment when it's needed renal replacement therapy. Dialysis: In the last 3-4 decades, irreversible chronic renal insufficiency was gradually transformed from a hopeless and progressive disease to a curable nephrology problem and this treatment extends patients' lives for many years. Many patients are living today over 30 years after they have completely lost their kidney function and that due to renal replacement procedures. This treatment extends patients' lives for many years, but does this treatment affect quality of life in patients with chronic kidney disease? The aim of this study is to identify the effects of hemodialysis in patients' quality of life. How dialysis patient affects physical activity, social activity, mental health and family relationships. What are the elements to improve the quality of life of dialysis patients? Methods: To gather information a questionnaire was used by "The survey questionnaire health generic Short-Form36 (SF36)", and personal contact with the subjects. Study is "qualitative-quantitative observer" type. There were inquired 48 patients at the dialysis center of "Tirana University Hospital". Criteria for inclusion in this study, was patients who are treated with hemodialysis by the dialysis center in TUHC (Tirana University Hospital Center) for a time of more than three months. Were excluded from this study patients who were treated with peritoneal dialysis and patients that were treated in other dialysis centers. The results: Looking at the answers given by the patients it was noted that renal replacement therapy is very demanding and affects the quality of life of patients. This treatment affected their professional life, many of them stopped being in working relationships and have acquired the invalidity status. A therapy that is repeated 3 times a week obstructs the patient and his family in

the social and economic contexts. In these patients it is observed an anxiety syndrome due to depression. Because of this therapy these patients experience a great sense of limitation in activities outside the family. The information that they have on dialysis is scarce and it was not given by the medical staff of the dialysis center. Conclusions: This study indicates that the life quality of dialysis patients is affected heavily by the treatment, and it is not enough to treat the disease but we should understand the effects that it has for the patient.

Key Words: Renal Insufficiency; Quality of Life (QoL); Renal Replacement Therapy.

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Introduction

Dialysis is defined as the diffusion of molecules in solution across a semi permeable membrane along an electrochemical concentration gradient. The primary goal of hemodialysis is to restore the intracellular and extracellular fluid environment that is characteristic of normal kidney function. This is accomplished by the transport of solutes such as urea from the blood into the dialysate and by the transport of solutes such as bicarbonate from the dialysate into the blood. Soluteconcentration and molecular weight are the primary determinants of diffusion rates. Small molecules, such as urea, diffuse quickly, whereas compartmentalized and larger molecules, such as phosphate, β_2 microglobulin, and albumin, and protein-bound solutes, such as p-cresol, diffuse much more slowly. In addition to diffusion, solutes may pass through pores in the membrane by means of a convective process driven by hydrostatic or osmotic pressure gradients — a process called ultrafiltration. During ultrafiltration, there is no change in solute concentrations; its primary purpose is the removal of excess total body water. For more than four decades, the standard schedule for hemodialysis has continued to be three sessions a week, 4-5 hours a day.

The present objectives for treatment of end-stage renal disease (ESRD) are 2-fold: in the first place to increase patient survival and in the second place to improve the quality of life of that survival. In order to improve the quality of life, it is essential to properly control the symptoms and complications of ESRD and work towards the full rehabilitation of the renal patient. Therefore, 'quality control' of medical care for these patients must be focused towards reaching these objectives. In this context, the evaluation of quality of life of the renal patient becomes an indispensable instrument in proving the effectiveness of therapeutic innovations, and in detecting those areas related to ESRD in which therapeutic effort, research or social support is most necessary. Over the past few years the therapeutic possibilities in the area of dialysis have changed greatly in, for example, the correction of anemia with erythropoietin (EPO), the general use of bicarbonate in dialysis, the more liberal use of special dialysis membranes, treatment with high doses of calcitriol to correct the severe hyperparathyroidism secondary to ESRD. These factors have probably had a positive influence on the quality of life of patients on dialysis, but extensive studies in which adequate indicators are used are needed to evaluate both the evolution of quality of life in patients on dialysis over time, and the influence of therapeutic changes and other factors on patient quality of life.

The quality of life of patients diagnosed with chronic renal insufficiency and their need to perform dialysis three times a week for 4 hours a day it is a very poor one. These patients think they are useless and this for various reasons such as, they cannot work and cannot provide or care for their families. They have a kind of inferiority complex that they express when upset. Regardless of the support and assistance received from the state, their economic situation is aggravated because of expensive medicines and of course the fact that they are not employed. This affects the progress of their daily lives but also emotional state, which is one of the key elements of quality life. For a large part of dialysis patients, independence is minimal. They need the support of a family member or guardian during or after dialysis, which makes them depended on others. This causes feelings of frustration, lack of independence, the sense of vulnerability and lack of intimacy. Dialyze affects physical activity, social activity and mental health for these patients and their relationships within the family.

The effect of social and family support of dialysis patients on QOL is significant in the literature. A review of family support among African American patients with kidney failure found to be varied from over-involvement to no support and social isolation from their family. Families as well as patients with chronic illness were at risk of high levels of stress (Holder, 1997). Family members experience stress for long periods of time and need to constantly adapt as the disease progresses (Newby, 1996). Family and marital relationships that have evolved prior to the patient becoming ill may be altered by the presence and attached responsibility to caring for a person on dialysis. It is known that the family's adaption is influenced by factors such as the quality of family relationships (Beanlands et al., 2005), cultural values and beliefs (Lindqvist et al., 2000).

Education level: It was expected that higher levels of education would positively promote healthy behaviors, and highly educated dialysis patients may volunteer to take some responsibilities of their own health and learn some strategies to cope with their disease and its symptoms Studies have found that factors such as dialysis duration (van Manen et al., 2001); educational level, physical functioning ability and co-morbidities were associated with the work status of patients undergoing dialysis treatment Several studies have reported a relationship between educational level and QOL. Each of the studies used a different QOL tool. Pakpour et al. (2010) studied 250 Iranian haemodialysis patients using the Persian version of the SF-36 and found that patients with lower level of education have poor QOL scores. Moreover, Acaray and Pinar (2005) studied the differences in the educational levels of four groups of dialysis patients (no formal education, primary school, secondary high school and university graduates). They reported that the overall total scores of the SF-36 increased as educational status increased.

Length of time on dialysis: Maesaka and Fishbane (2001) evaluated the QOL of 134 American haemodialysis patients using the SF-36 three-monthly over two years. They found that the number of months on haemodialysis had a significant inverse relationship with the changes in physical function, body pain and general health vitality subscales scores of the SF-36. Pakpour et al. (2010) found that the longer time on dialysis correlated with poor SF-36 scores.

Educational and psychological: Interventions can produce important benefits for dialysis patients. Pre-dialysis psycho-educational interventions, for example, can enhance illness-related knowledge (Mehrotra, Marsh, Vonesh, Peters, & Nissenson, 2005) and promote QOL (Fukuhara et al., 2006). Several studies have demonstrated that early referral to nephrologists decreases

morbidity, mortality and healthcare costs (McLaughlin, Manns, Culleton, Donaldson, & Taub, 2001); improves long-term survival (Jungers et al., 2001); reduces the need for urgent dialysis (Schmidt, Domico, Sorkin, & Hobbs, 1998); and improves health-related QOL in dialysis patients (Korevaar et al., 2002)

Methodology

The purpose of this study was: To identify the effects of hemodialysis in patients' quality of life. The study's specific objects:

- 1- How much does hemodialysis affect the physical activity of the patient?
- 2- How much does hemodialysis affect the mental health of the patient?
- 3- What are the elements could improve the quality of life of patients.

Materials and Samples

The study was conducted at the dialysis center at "Tirana University Hospital" over the period of April and May 2013. To gather information a questionnaire was used by "The survey questionnaire health generic Short-Form36 (SF36)", and personal contact with patients. Study is "qualitative-quantitative observer" type. There were inquired 48 patients at the dialysis center of "Tirana University Hospital", patients were randomly selected. The questionnaire contained multiple choice questions and was completed voluntarily. A criterion for inclusion in this study was patients who are treated with hemodialysis dialysis center in TUH (Tirana University Hospital) for a time period of more than three months. Were excluded from this study that patients treated with peritoneal dialysis and patients who are treated in other dialysis centers. The data were collected in five areas: 1:Knowledge of patient on dialysis. 2:Physical activity. 3:Social activity. 4:Impact on family relationships. 5: Impact on mental health.

The Statistical Analysis of the Data

For numerical variables were reported central tendency magnitudes (arithmetic mean, median and mode) and magnitudes of dispersion (variance, standard deviation and interquartile range) for categorical variables were reported the respective numbers and percentages. It uses descriptive analysis of variables and Meta analysis was conducted to compare the results of other obesity studies with our study.

Statistical tests were used for two and for more than two independent samples, to find the value of P or the α error with 95% confidence interval (CI)

Statistical processing was focused on two main components which were:

1. Descriptive-Quantitative part:

- For categorical variables were reported the respective numbers and percentages;
- For numeric variables, respective averages were reported ± standard deviations (Eg. age)

2. Analytical part: where links (dependencies) of the variables in the study were analyzed as follows:

- **Bivariate analysis**: The link of individual characteristics and other variables of interest.
- **Multivariate Analysis**: All multi-variable models were simultaneously searched for the following variables:
- Demographics and socio-economical factors; age, gender, education and economical level.
- Factors associated with lifestyle: eg. Daily activity.
- Other factors of interest: antidepressants and their use, or some indicators that testifies to the lack of quality of life.

Since it is the first qualitative-quantitative type of study, in the third part includes results and analysis of interviews, focus groups and qualitative questions in the questionnaire data. There are data processed by Grounded Theory, which aims to synthesize the responses and qualitative data and allow the Researcher to operate with these data. They used different statistical tests in the quantitative part, to compare our variables and it was observed the significance of changing the entire data. A statistical analysis of the data was conducted in SPSS (Statistical Package for Social Sciences, version 15.0, Chicago, IL).

Results

Table 1. Age Group

35.4% of diagnosed patients with IRK belong on the age group of 46-55 years old. Less affected age group is from 26-35 years old. 6.3%

Age Group									
		Frequency	Percentage	Valid Percentage	Cumulative Percentage				
	Up to 25 years	4	8.3	8.3	8.3				
	26 to 35 years	3	6.3	6.3	14.6				
Variables	36 to 45 years	11	22.9	22.9	37.5				
variables	46 to 55 years	17	35.4	35.4	72.9				
	Over 56 years	13	27.1	27.1	100.0				
	Total	48	100.0	100.0					

Table 2. Patient Level of Education

43.8% of the patients have low level of education, 47.9% have medium level of education 8.3% have high level of education.

Patient Level of Education									
				Valid	Cumulative				
		Frequency	Percentage	Percentage	Percentage				
Variables	Low	21	43.8	43.8	43.8				
	Medium	23	47.9	47.9	91.7				
	High	4	8.3	8.3	100.0				
	Total	48	100.0	100.0					

Table 3. Employment

81.3% have the disability status; 8.3% are retired, 6.3% are employed and 4.2% are unemployed

Employment										
		Frequency	Percentage	Valid Percentage	Cumulative Percentage					
	Unemployed	2	4.2	4.2	4.2					
	Employed	3	6.3	6.3	10.4					
Variables	Invalid (disabled)	39	81.3	81.3	91.7					
	Retired	4	8.3	8.3	100.0					
	Total	48	100.0	100.0						

Table 4. Nr. years of Dialysis

83.3% of patients were in first 5 years of dialysis, and only 2.1% were in15-20 years of dialysis.

Nr. years of dialysis							
	Frequency	Percentage	Valid Percentage	Cumulative Percentage			
1-5 years	40	83.3	83.3	83.3			
5-10 years	5	10.4	10.4	93.8			
10-15 years	2	4.2	4.2	97.9			
15-20 years	1	2.1	2.1	100			
Total	48	100	100				

Table 5. How much are you informed on dialysis?58.3% have poor information on dialysis.27.1% have no information at all.6.3% are very informed on dialysis.

How much are you informed on dialysis ?										
		Frequency	Percentage	Valid Percentage	Cumulative Percentage					
	No Info.	13	27.1	27.1	27.1					
Variables	Little Info.	28	58.3	58.3	85.4					
	Medium Inf.	4	8.3	8.3	93.8					
	Very inf.	3	6.3	6.3	100.0					
	Total	48	100.0	100.0						

Table 6. How is the dialysis costs covered?

64.6% of the patients themselves cover dialysis costs (transportation, purchase of medicines, etc)

22.9% of the patients receive the support from their relative and family to cover dialysis costs

12.5% of the patients receive support from state.

How is the dialysis costs covered?									
FrequencyPercentageValid PercentageCumulative Percentage									
	Themselfes	31	64.6	64.6	64.6				
Variables	Relatives	11	22.9	22.9	87.5				
	State	6	12.5	12.5	100.0				
	Total	48	100.0	100.0					

Table 7. How do you think your condition affects the lives of your relatives?

58.3% of patients responded that their condition affects their families considerably. Their disease has an impact not only on them but also to their family.

How do you think your condition affects the lives of your relatives?									
FrequencyPercentageValidCumulative PercentageFrequencyPercentagePercentagePercentage									
	Low	8	16.7	16.7	16.7				
Variables	Medium	13	27.1	27.1	43.8				
v arrables	Highly	27	56.3	56.3	100.0				
	Total	48	100.0	100.0					

Table 8. How often do you feel hopeless?

37.5% rarely feel hopeless, 33,3% often feel hopeless and only 2.1% more frequently feel hopeless.

How often do you feel hopeless?									
		Fraguanay	Dorcontago	Valid	Cumulative				
		requeicy	reicentage	Percentage	Percentage				
	Never	13	27.1	27.1	27.1				
	Rarely	18	37.5	37.5	64.6				
Variables	Often	16	33.3	33.3	97.9				
	Frequently	1	2.1	2.1	100				
	Total	48	100	100					

Table 9. Have you ever taken antidepressant?

91.7% of patients receive antidepressant frequently, 4.2% rarely receive antidepressant.

Have you ever taken antidepressant?									
		Fraguenay		Valid	Cumulative				
		Frequency	reicemage	Percentage	Percentage				
	NO	2	4.2	4.2	95.8				
Variables	Rarely	2	4.2	4.2	91.7				
variables	Often	44	91.7	91.7	100.0				
	Total	48	100	100					

Table 10. What do you do on the days without dialysis?

37.5% of the patients spend most of their time at home in front of the TV. 10.4% goes for a walk outside.

What do you do on the days without dialysis?										
		Fraguanay	Dorcontago	Valid	Cumulative					
		Frequency	Fercentage	Percentage	Percentage					
	Walking	5	10.4	10.4	10.4					
	Reading	8	16.7	16.7	27.1					
Variables	Going out with friends	17	35.4	35.4	62.5					
	Watching TV	18	37.5	37.5	100.0					
	Total	48	100.0	100.0						

Table 1	1. Ho	w many	hour	s do	you sle	ep at n	ight?		
43.8%	of the	patients	sleep	4-5	hours.	14.6%	sleep	5-7	hours.

How many hours do you sleep at night?									
FrequencyPercentageValidCumulativePercentagePercentagePercentage									
1-3 hours		20	41.7	41.7	41.7				
Variables	4-5 hours	21	43.8	43.8	85.4				

5-7 hours	7	14.6	14.6	100.0
Total	48	100.0	100.0	

Table 12. How do you find your life quality?

54.2% of the patients have a bad qualitative life.3% of the patients have god qualitative life

How do you find your life quality?								
		Frequency	Percentage	Valid Percentage	Cumulative Percentage			
Variables	Bad	26	54.2	54.2	54.2			
	Good	19	39.6	39.6	93.8			
	Very good	3	6.3	6.3	100.0			
	Total	48	100.0	100.0				

Table 13. What do you think of the dialysis treatment service?

58.3% of the patients think that dialysis treatment service is sufficiently good. 8% of the patients think that the dialysis treatment service is bad.

What do you think of the dialysis treatment service?								
		Frequency	Percentage	Valid Percentage	Cumulative Percentage			
Variables	Bad	8	16.7	16.7	16.7			
	Sufficient	28	58.3	58.3	75.0			
	Very good	12	25.0	25.0	100.0			
	Total	48	100.0	100.0				

Discussion

Looking at the answers given by the patients noted that renal replacement therapy is very demanding and affects the quality of life of patients. It affects their professional activity, 81.3% of patients claim that are not in working relations and have received disability status.

The stresses resulted from being financially dependent along with difficulties in coping with family responsibilities, and social lives leads to mood swings and unfulfilled hopes. Patients with chronic illnesses encounter stressful situations in their work environment.

The results of the study show that the level of education of dialysis patients generally is low. 43.8% of them are of a low education. This link shows that educational level is connected with the quality of life of patients. It was expected that higher levels of education would positively promote healthy behaviors, and highly educated dialysis patients may volunteer to take some responsibilities of their own health and learn some strategies to cope with their disease and its symptoms.

One other factor that affects the QoL of patients is the number of years on dialysis. Number of years in dialysis affects the changes of bodily functions, and manifests itself in bodily pain, in general health and vitality. The length of time on dialysis could lead to the extension of suffering from the consequences of kidney failure.

By the words of patients on hemodialysis it is indicated that problems associated with a chronic therapy that is repeated 3 times a week not only hinders the patient but also the family, in their social context. Families are forced to support a person who in this condition has more needs. Their families are required to support the patient financially, because the state only covers a small part of the cost of dialysis. 56.3% of the patients claim that their health condition affects their families too.

Patients are required to provide their own transportation to the dialysis center. Many patients who come from districts have to rent a house in Tirana to minimize travel costs of 3 times a week from districts. Large part of the patients state that they have to cover the cost for dialysis themselves and sometimes with the help of their relatives.

The patient's condition affects many their family members lives. Patients are required to follow a certain diet; they often have mood swings, and also exhibit chronic psychological problems. According to data obtained by the psychologist who follows the patients at the center of dialysis in UHT (University Hospital Tirana), half of patients exhibit signs of Anxiety and Depression.

Due to this illness patients and their families are subjected to continuous strain which is hard to withstand. Illness forces sick of his family in a continuous strain on the tension that is difficult to confront. We shouldn't be suppressed that even those who seem well show depressive and aggressive behavior.

The family usually takes the sick person to the hospital and works closely with the healthcare team to provide the best treatment and support. It is expected that dialysis patients have a great deal of psychological and physical stressors that require family and social supports as well as physical and psychological adaptation to the changes in their role and ability to fully function in society. The availability of family members and other support systems will have a positive impact on the QoL of dialysis patients.

As far as social and interpersonal relationships go, according to this study conducted at the University Hospital Center, it turns out that most of the patients spend their time with their families, friends, some go for walks, the rest dedicate themselves to light activities such as reading. The study points out that there is a great sense of limitation of outside activities because of dialysis therapy.

Information they have on dialysis is scarce and this information was not given to them by the medical staff of the dialysis center, but many of them acquired it on their own through internet or reading.

Knowing about the illness can help dialysis patients understand the disease process better and helps them in finding ways to decrease the pain and other

associated symptoms . Patients with kidney failure have to take multiple medications and follow strict diet regime. Knowing more about their disease helps them cope with it and improve their QOL. SF-36 measures the functional abilities of the respondents. Therefore, respondents who knew the cause of their kidney failure were more able to cope with their functional limitations.

Conclusions

Dialysis plays an important role in the survival of people with IRK and an important role and determining their quality of life. Hemodialysis is perceived by medical staff as "the worst", and the only reason (direct or indirect) that causing all the pain of the patient. So family needs and concerns are ignored, social and psychological problems and issues which if carefully confronted can profoundly improve patient conditions, turning the energy and motivation to face the treatment. In fact it is not enough to intervene in the disease, but one should understand the significance that it has to the patient.

It is essential that patients be given correct information regarding hemodialysis procedure, care for vascular access (major complications, management and sanitation) diet, fluid restrictions, the kind of life they will have, and the potential consequences of pathologies which may be caused by the duration of the dialysis itself.

This study showed us out that this information was not issued at hemodialysis center in UHT.

Studying QOL can benefit both dialysis patients and healthcare professionals. Dialysis patients may gain more insight about their stressors and limitations. This consequently will provide them with the opportunity to investigate their coping skills, which may help them identify poor adaptation techniques and develop healthier coping strategies. Healthcare professionals, especially nurses, spend considerable time with patients treating their chronic conditions. So, they are in a good position to take creative measures to improve the QOL of patients with long term conditions.

Furthermore, studying the QOL should help nurses and other healthcare professionals gain knowledge and an in-depth insight of the contributing factors to better QOL among dialysis patients, so they can plan treatment by setting up specific, realistic, measurable and achievable goals.

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