Investigating overall health and life quality of patients undergoing dialysis in chronic dialysis units

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INVESTIGATING OVERALL HEALTH AND LIFE QUALITY OF PATIENTS UNDERGOING DIALYSIS IN CHRONIC DIALYSIS UNITS

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Abstract

Background: Dialysis patients experience intense psychological and emotional changes and symptoms that affect their daily quality of life.

Aim: The aim of this study is to investigate the factors affecting the overall health and life quality of patients undergoing dialysis.

Methods and Material: This cross-sectional study involves 49 patients undergoing dialysis, during June and August of 2019 in the hemodialysis units in Athens. Intentional sampling was used as the sampling method and the research tool was the questionnaire (KDQOL-SF ™ –2009). IBMSPSS 25.0 was used for data analysis. Frequency distributions were calculated, 95% confidence intervals with bootstrap techniques, while the non-parametric rho-Spearman correlation coefficients of the KDQOL-SF subscales were also calculated and followed by multiple linear regressions of the Total Health Scale that determine the quality of life.

Results: The most important and positive findings regarding the quality of life of the participants were the social support the patients received 57.1%, the encouragement from the staff of the nephrology department 44.9%, the cognitive function 82.4%, and patients satisfaction 84.3%, while work status 16.3%, pain 64,4%, sexual function 37%, the physical function 58.8%, scored the worst results. Scores representing the emotional well-being of the patient, a value closely related to the quality of life, were moderate.

Conclusions: The present study shows the need for intervention planning for patients with ongoing monitoring, as well as creative employment and work programs to achieve an improvement in their overall health and quality of life.

Keywords: Hemodialysis, quality of life, health-related quality of life, chronic kidney disease.

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INTRODUCTION

The estimate for the existence of kidney patients in Greece reaches 1,000,000, i.e. 10-11% of the population, while 12% of kidney patients are considered to be in a final stage. Of the substitution methods come to approximately 14,200 according to recent data from the Transplantation Coordination and Control Service. According to studies, the mortality of terminally ill patients in Greece is 10-20 times higher greater than that of the general population.[1]

In recent decades, with the advancement of technology and medical science, there has been an increase in life expectancy for patients undergoing dialysis, while health professionals are showing increasing interest in investigating the effects of kidney disease on the mental health of these patients. Hemodialysis is the most common method of renal replacement with better clinical indicators compared to other methods.[2] More specifically, its application is periodic, usually three times a week, and takes place in the Artificial Kidney Units in hospitals and more rarely in the patient's home. The time taken in these hemodialysis sessions is precious and greatly effects the quality of everyday life of the patient. The altered self-image, the anxiety regarding death, the uncertainty concerning the course of the disease combined with social, family, and professional roles, and even the waiting time for the transplant, are just some of the factors that determine the stressful situation which the patients experience.[2]

Dialysis patients suffer from various physical and emotional disorders, they show symptoms of depression while experiencing significant changes in their quality of life. These symptoms include fatigue, pain, muscle cramps, insomnia, sexual disfunction and affect more than half of patients with end-stage renal disease. The depressive behaviour of patients undergoing dialysis seems to affect their quality of life. First, although there are 20 million registered patients with chronic kidney failure in the United States, that number is set to increase if patients with hypertension and diabetes continues to rise. Understanding how depression affects this large number of patients will help to implement methods aimed at improving their quality of life. Second, studying the severity of the general symptoms of renal failure as well as the depression that affect patients' quality of life

will help in the better understanding of their general condition and how the various symptoms will occur as they progress through the course of the disease.[3]

It has been observed that 20-30% of patients on dialysis suffer from depression, significantly increasing mortality rates, sexual dysfunction in male patients, as it reduces the motivation for self-preservation. Regular re-admissions to hospitals are noted, while there are also those who decide to stop the treatment of renal replacement. Patients undergoing dialysis have an 84% chance of committing suicide and suicidal acts, compared to the general population. A patient undergoing long-term dialysis does not appear to have a particularly significant chance of developing a depressive disorder. In contrast to other studies, gender, family, and marital status do not play a statistically significant role in the occurrence of depression. Finally, good relations between patients and staff are considered beneficial, as the first to declare better relations with the staff members of the department show lower rates of depression.[4]

According to empirical data, dialysis patients experience psychological and emotional changes due to their dependence on the dialysis machine and the uncertainty of the disease. Chronic pain is an important aggravating factor for most patients and thus insomnia is not absent state. In these waking hours depression can manifest. Other symptoms such as anxiety, fatigue, drowsiness during the day, obstructive sleep apnea and restless legs syndrome, similarly affect the emotional and mental state of patients and their quality of life.[5]

In a study, Spaniards with chronic kidney disease found that quality of life was an important measure of patient well-being as low scores led to increased mortality.[6] Most studies on the quality of life include people with end-stage renal disease and exclude pre-renal replacement patients or transplant recipients.[6] Of course, this distinction is not surprising as patients who are in the final stage of renal insufficiency are the majority in comparison toother categories, and in the case of the Spaniard, are ever increasing. Among Americans and Spaniards living with chronic illness, Spaniards appear to have a better quality of life than Americans.[6]

In a study conducted in three Athenian hospitals, 144 kidney pa-

tients, 84 dialysis patients and 60 who undergo continuous portable peritoneal dialysis were involved. A questionnaire was used to measure quality of life as perceived by patients, including questions about physical health, psychological health, social relationships, and the environment. Elderly patients reported that their quality of life was affected by it, but more specifically what was affected were their general physical condition and social relationships. In addition, the patients with a high level of education, considered their quality of life good in relation to their environment, while married patients considered their quality of life good in relation to psychological health and their social relationships. There was a negative correlation between the stress factors and the areas of quality of life concerning psychological health and the environment. Finally, the participants' perception of mental health was negatively correlated with their physical health.[7]

The purpose of this study was to investigate the factors affecting the overall health and quality of life of patients undergoing dialysis.

METHODOLOGY

Study Design, Sample and Participants

The population of this cross-sectional study was designed and consisted of patients with end-stage renal disease on dialysis. The study was conducted in two general hospitals in Athens during the summer months of 2019. The intentional sampling method was used as the sample had the same characteristics. The total number of patients under hemodialysis was 49. The participants in the study were 49 patients.

Research tool

The main tool used for this study was the Kidney Disease and Quality of Life (KDQOL-SF ™ 2009) structured questionnaire. The questionnaire includes 24 questions about patients' history and quality of life and identifies 19 components of which 11 are symptomatic and 8 express the quality of life of patients. Subscales include patient satisfaction, staff encouragement, social support, sleep quality, sexual function, social interaction, cognitive function, work, disease burden, disease effects, symptoms

while those related to quality of life were physical function, emotional role, physical pain, general health, emotional well-being, vitality, social function, and physical role. The relative score of the subscales is on a scale of 0-100 and results as the average weighting of the questions that make up each component. An increased score (close to 100) indicates fewer symptoms or problems, better functionality and generally a good quality of life. Reliability was assessed with the Cronbach alpha coefficient except for the components consisting of one question.[8]

Data Collection

The data was personally collected by the researchers at the dialysis units in Athens. The survey was conducted from June 2019 to August 2019. Following the briefing and verbal consent of the directors for the study implementation, patients were informed about the purpose of the study and assured of the anonymity of participants. The researchers received written consent from the participants to take part in the study.

Ethical considerations

Ethical approval was obtained from the Research and Bioethics Committee (IRB; 267/May15, 2019 and, 11500/April18, 2019). The participants in the study were informed about the study objectives, expected outcomes, and associated benefits and risks. Written consent was received from the participants before they answered the questionnaire. Permission to use the hospital facilities was also obtained by the author prior to data collection.

Data Analysis

IBMSPSS 26.0 was used for data analysis. Frequency distributions of the baseline characteristics of the 49 patients undergoing dialysis were calculated with a case-by-case estimate of 95% confidence intervals. Friedman control was used to compare subscale levels. The non-parametric rho-Spearman correlation coefficients of the KDQOL-SF subscales were also calculated, which determine the quality of life between them and in terms of patient, personal, disease and hospital characteristics. Finally, for the determination of factors related to overall health and quality of life, multiple linear regression of the Total Health scale was followed, with the characteristics of the patients as well as

the ease of access to the dialysis center. A significance level of 0.05 was set.

RESULTS

A total of 49 hemodialysis patients were enrolled in the study (Table 1). 59.2% were males, while the mean age for all genders was 57.9 ± 12.6 years, 65.3% stated that they were married or engaged and 34.7% were divorced or unmarried, while 75.5% of them had children. 32.7% were primary school graduates or 16.3% held a Higher Education degree. 91.8% declared Greek nationality and in terms of their monthly income 10.2% exceeded € 1,500 per month. Finally, most patients or 89.8% stated that they lived in a large urban area.

Table 2 presents the hospitalization and illness characteristics of the 49 participants. The mean value for dialysis years was 7.9 years (± 6.9), with a mean age at onset of 50 years (± 12.9). For 63.3% the access to dialysis center was easy, that is, they went without the help of another person, and most (65.3%) used a car as a transport vehicle (relatives' car), that means they needed someone's help to move. The most important causes that led to hemodialysis, Polycystic Kidney Disease scored a percentage of 28.6%, while Diabetic Kidney Disease and Hypertension scored a percentage of 20.4% respectively.

Table 3 presents the summary measures of KDQoL-SF scale scores. An elevated value on the scale means no symptoms or good quality of life, while the top percentage is 100 and means no symptoms. Among the highest percentages were Social support (57.1%) and encouragement from the staff of the Hemodialysis unit (44.9%). In contrast, the threshold is the value 0 (= severe symptoms) where a high proportion of patients have low levels of work status (73.5%) or physical functioning (53.1%). In general, the average score of General Health is moderate (57.9) while with a lower average score, the working status (16.3) and higher the encouragement of the Hemodialysis staff (88.5). The worst value was scored by the Physical role, i.e. physical strain, (22.0) compared to the highest and best value for Emotional well-being (68.5) (p < 0.001). In addition, the Overall Health rating shows excellent consistency of responses (excellent reliability).

Additionally, Figure 1 shows the hierarchical distribution of median values in components of KDQoL-SF scale scores. So, it seems that half of the patients have an Overall Health rating score up to 58.2, while higher median values (better quality of life) are observed in Pain (77.5) or Social function (75.0). In the absence of symptoms, at least half have the highest score in the Dialysis staff encouragement (100.0 or complete absence of symptoms) or in the Cognitive function above 93.3. It is noted that in Role-physical but also in Work status, at least half of the patients have the worst quality of life or complete presence of symptom, respectively.

In addition, women appear to have a worse quality of life in Work status (rho-Spearman = -0.295, p <0.05) or in Role-emotional (rho = -0.298, p <0.05) have significantly less pain(rho = -0.559, p <0.05) and higher Overall Health rating or better quality of life (r = -0.469, p <0.05) while most dialysis years involve worse Burden of Kidney disease (rho = -0.381, p <0.05) (results not shown in Table or Figure). Among the components of KDQoL-SF scale, the highest correlation is observed between Social support with Sleep (rho = 0.791, p <0.01) or Symptom / problem list (rho = 0.620, p <0.01) and Patient satisfaction with Dialysis staff encouragement (rho = 0.675, p <0.01)

Finally, from table 4 through the multiple linear regression analysis it is observed that the highest score or the best quality of life is significantly related to the younger age of the patients (β = -0.40, p = 0.020) or to the degree of easy access to the Dialysis Center (β = -6.42, p = 0.020). In addition, there seems to be a marginally insignificant correlation of the highest score or better quality of life with the fewest years of dialysis (β = -0.65, p = 0.055).

DISCUSSION

The aim of this study was to investigate the overall health and quality of life of hemodialysis patients. The mean value for dialysis years was 7.9 years (± 6.9) with a mean age of onset of 50 (± 12.9) years. Access to the dialysis center was easy for 63.3% of the patients while the age of the patients and their ease of access to the dialysis center have a significant negative correlation as higher scores or better quality of life are correlated with younger ages or those with easier access to the dialysis center.

It also seems that the years of dialysis are not negatively related. It is observed that women had a lower quality of life at work and their Emotional role due to their low scores. Younger ones scored higher in Disease Effects and Overall Health which indicates that they were less affected. Functionality, Physical Role, General Health, Sexual Functionality and Physical Pain. Men were found to have the largest percentage of participants with an age distribution of all participants of 57.9 years (± 12.6). The most important findings regarding the quality of life of the participants were the social support of the patients, the encouragement of the staff, the cognitive function, and the physical role, while the lowest scores were received for work, pain, sexual and physical function, and the severity of the kidney disease. Emotional well-being, which is closely corelated to the quality of life, was moderate.

Duarte et al., Studying patients undergoing dialysis in Brazil with 55% being male, observed a positive quality of life in components such as cognitive function, social interaction and encouragement from the unit staff and negative consisted the areas of physical and sexual function, and emotional well-being.[9] Consistent with the present study, several more were found, adding to the negative components the stress experienced by patients, as well as work difficulties. In particular, a study conducted in South Africa in 2017 identifies components that agree with some of the present study. More specifically, a statistically significant difference is observed in social functioning, emotional well-being, working status, sexual function, participants' fatigue, and symptoms of the disease, constituting the parameters that negatively affect the quality of life, while encouragement by staff has been shown to promote their quality of life and the care provided leads patients to consider it a '' family ''.[10]

In addition, social support, and interaction with the patient's environment, as well as support and encouragement from the staff seem to be in most studies the most important areas that positively affect patients and improve their quality of life.[11]

However, in the same study, negative parameters were observed, with the emotional role prevailing due to the reduced emotional health and the emotional and psychological weight that patients feel from the symptoms and manifestations of the disease.[11] Regardless of the early or advanced stage of dialysis,

patients' daily lives are constantly changing. As mentioned in the present study, inability to work, stress and difficulty sleeping were among the parameters that seemed to significantly affect the quality of life of patients. Consistent with these findings was research by Theodorou et al., 2020,[12] who concluded that sleep difficulties are due to the generalized anxiety of patients from the disease and dialysis in general. So, patients not only suffer from insomnia but also from difficulty in sleeping and maintaining sleep, as well as from restless sleep when it finally occurs. Insomnia also seems to be caused due to the limitation of physical activities and the mental and social condition of patients who are constantly changing.

Older patients, while as is expected, are affected physically over the years undergoing dialysis, do not appear to be significantly affected mentally, their social life, and their general outlook on life. Contrary, the research of Ayumi et al., 2020 [13] claimed that as the years of dialysis increase, the patients are significantly affected by the severity of their symptoms, while also with the beginning of the treatment, their satisfaction with life decreases. There was a need for social and psychological support from both specialists and the family environment. These results were also agreed upon in the study of Theophilou et al. 2010 and Kousoula et al 2015.[14,15]

Ramatillah et al., found that in addition to the negative components that have already been reported by other studies but also by this study such as social functionality, emotional well-being, etc., they also report cognitive function, satisfaction of patients, social interaction and social support, where in most studies there is a positive effect on the quality of life of patients and not a negative one.[16]

Several studies on the quality of patient's life in Iran have shown that dialysis patients have a lower quality of life than patients with other chronic diseases. In one of these studies, components related to the physical and social functionality of the patients had the highest score. The lowest, on the other hand, were collected by the components concerning the emotional state and the perceptions of the patients about their health. Also in a similar study, the general psychological state of women seemed to affect them to a degree that determines the general perception they have about their health and the disease they suffer from

and the way they perceive it.[17,18] Another study conducted in Saudi Arabia in 2011 found that most patients reported limited physical and emotional role, as well as limited work status and cognitive function.[19]

In a study conducted in Indonesia on the quality of patients' life undergoing dialysis, pain and stress factors had the lowest scores. In fact, there were many cases of severe depression which may have improved after some time in dialysis either due to improved urea and creatinine levels, or patients' awareness of their condition. In addition, financial problems, difficult living conditions with high costs and the inability to work are factors that cause many psychological problems both in patients and in their environment. At this point there is an interesting difference between the research in Indonesia and the present study, where in the latter, although the emotional well-being of the individual is certainly negatively affected by the nature of the disease, it does not particularly affect the individual and does not cause problems in his socialization. On the contrary, patients' emotional well-being was one of the components that had good scores and also based on the data collected, participants had particularly good relationships with those around them.[20]

Limitations

There were some limitations in the context of data collection for this study. There were losses during data collection since some individuals refused to fill in the questionnaires for personal reasons. Furthermore, this study was conducted in only two Haemodialysis units, so it is not representative of other units of Greece.

CONCLUSION

As discussed in the present study, factors such as work, decreased sexual function, the severity of kidney disease, the ever-changing physical condition and the emotional well-being appeared to affect the patients' daily lives. Most participants considered their health to be in a mediocre condition, although their cognitive function, the social support received from their environment and their satisfaction with the provided health care services as well as the support from the staff of the dialysis center, are considered to be good. These parameters help to under-

stand that the institution of the family and the patients' sociability has been and always is of paramount significance and with the active involvement of the family in every aspect of the patient's health determines to a significant degree the progression of the disease. As far as health professionals are concerned, the fact that patients applaud the health services provided and the former show interest and approach them individually and not just as incidents to be dealt with, demonstrates the professionalism but also the need for continuing education to help in the long run and in the overall design of their health care.

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ANNEX

Table 1. Descriptive characteristics of 49 haemodialysis patients of current study.

		n	%
Gender	*males*	29	59.2
	females	20	40.8
Age, *years*	*meanage±stand. dev. (min., max.)*	57.9±12.6 (23. 82)	
Education	*primary school*	16	32.7
	gymnasium	7	14.3
	lyceum	12	24.5
	University or Technological School	8	16.3
	Master or PhD	6	12.2
Family status	*unmarried, divorced*	17	34.7
	married, in relationship	32	65.3
Children	*no*	12	24.5
	yes	37	75.5
Ethnicity	*Greek*	45	91.8
	other	4	8.2
Monthly income	*<€500*	8	16.3
	500-999	22	44.9
	1,000-1,499	14	28.6
	1,500+	5	10.2
Place of residents, *inhabitants*	*≤20,000*	5	10.2
	>20,000	44	89.8

Table 2. Characteristics of hospitalization and disease of 49 hemodialysis patients of current study.

		n	%
Hemodialysis years	*mean±stand. dev. (min., max.)*	7.9±6.9 (1. 30)	
Age of onset, *years*	*meanage±stand. dev. (min., max.)*	50.0±12.9 (11. 74)	
Access to a center:	*easy*	31	63.3
	Neither easy, nor difficult	9	18.4
	difficult	9	18.4
Transport Methods	*taxi*	9	18.4
	Car(relatives)	32	65.3
	ambulance	2	4.1
	Public transport	5	10.2
	other	2	4.1
Cause of dialysis	*Diabetic Nephropathy*	10	20.4
	Hypertension	10	20.4
	Glomerulonephritis	8	16.3
	Ischemic Kidney Disease	3	6.1
	Polycystic Kidney disease	14	28.6
	Renal artery stenosis	4	8.2
	Unknown etiology of CKD	7	14.3
	Other	3	6.1

Table 3. Summary measures of KDQoL-SF scale scores of 49 haemodialysis patients of current study.

components	mean	stand. dev.	% floor	% ceiling	skewness	Cronbach α
Symptom/problem list	72.1	13.1	-	-	-0.73	0.751
Effects of Kidney disease	53.0	18.5	-	-	-0.36	0.692
Burden of Kidney disease	48.5	22.6	2.0	-	-0.35	0.613
Work status	16.3	29.6	73.5	6.1	1.67	0.409
Cognitive function	82.4	20.1	-	36.7	-1.08	0.776
Quality of social interaction	78.8	18.3	-	14.3	-0.85	0.618
Sexual function	37.0	38.5	42.9	10.2	0.40	0.870
Sleep	67.7	26.3	-	6.1	-0.71	0.893
Social support	50.9	21.1	-	57.1	-0.01	0.558
Dialysis staff encouragement	88.5	15.9	-	44.9	-1.17	0.644
Patient satisfaction	84.3	18.0	8.2	-	-0.90	--
Physical functioning	58.8	30.7	53.1	8.2	-0.75	0.939
Role-physical	22.0	30.4	6.1	38.8	1.40	0.714
Pain	64.4	36.1	2.0	-	-0.42	0.956
General health	32.0	18.8	-	2.0	0.44	0.690
Emotional well-being	68.5	19.9	34.7	40.8	-0.52	0.787
Role-emotional	52.4	44.6	-	-	-0.08	0.864
Social function	65.1	25.0	-	8.2	-0.57	0.464
Energy/fatigue	58.0	23.3	-	-	-0.71	0.825
Overall Health rating	57.9	15.6	-	-	-0.14	0.956

Friedman test between the eight components of quality of life scale (SF-36), p<0.001.

Table 4. Multiple linear regression analysis of Overall Health rating score (KDQoL-SF scale)in relation to characteristics of 49 hemodialysis patients.

predictors	Overall Health rating			
	β	95%CI		p-value
Gender (1:males, 2:females)	-2.71	-11.78	6.36	0.549
Age (years)	-0.40	-0.74	-0.07	0.020
Education (1: primary school, 2:gymnasium, 3:lyceum, 4:University or Technological School, 5:Master or PhD)	-0.47	-3.41	2.48	0.750
Family Status (1: unmarried, divorced, 2:married, in relationship)	-2.25	-11.11	6.62	0.611
Children (1:no, 2: yes)	2.11	-7.63	11.86	0.664
Monthlyincome (1:<€500, 2: 500-999, 3:1,000-1,499, 4: 1,500+)	4.50	-0.90	9.90	0.100
Hemodialysis years	-0.65	-1.32	0.02	0.055
Access to a center (1:easy, 2: neither easy nor difficult, 3: difficult)	-6.42	-11.77	-1.06	0.020
R^2(adjusted)	0.409 (0.290)			

Figure 1. Hierarchical distribution of median values incompetents of KDQoL-SF scale scores of 49 hemodialysis patients of current study.