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Research Article

Evaluation of Quality of Life and Fatigue in Dialysis Patients: The Contribution of Social Support and Satisfaction from Nursing Staff

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Abstract: Introduction: Health-related quality of life in patients undergoing dialysis decreases over time, not only due to the treatment of the disease but also due to the reduction of physiological, psychological and social well-being. **Aim:** The aim of this research is to study social support and nursing care that patients with dialysis receive, their levels of fatigue and their quality of life. In addition, the effect of social support and nursing care on the patients' levels of quality of life is examined. **Methodology:** A quantitative cross-sectional study was conducted using the questionnaires "Multidimensional Scale of Perceived Social Support", Fatigue Assessment Scale (FAS), Missoula-VITAS Quality of Life Index and nursing care. The study involved 69 patients on dialysis. **Results:** Interpersonal relationships were associated with social support (p <0.01). Quality of life was associated with social support (p <0.05). **Conclusions:** It seems that there is a strong association between social support and quality of life in patients on dialysis.

Keywords: Dialysis, Quality of Life, Fatigue, Social Support, Nursing Care

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1. Introduction

Hemodialysis is a complex procedure for a patient that requires frequent visits to hospitals or dialysis centers, mostly 3 times a week, which implies substantial changes in the patients' normal lifestyle. 92% of dialysis patients may experience a high symptom burden and may experience bothersome symptoms such as fatigue, decreased appetite, concentration problems, swelling in their legs and arms, and muscle cramps, all of which cause daily discomfort and negatively affect QOL [1].

Hemodialysis is a time-consuming and expensive treatment and requires more restrictions on diet and fluid intake, as mentioned. Long-term hemodialysis causes loss of freedom, dependence on the caregiver, disruption of marriage, family, social life and reduction or lack of income. All these factors affect QOL [2]. Many studies have found that CKD patients complain of depression and other mental symptoms. On the other hand, little is known about patients' and caregivers' health problems and their QOL [3].

Dialysis-dependent patients with CKD face severe limitations, including strict adherence to dialysis treatments and medications, dietary and fluid restrictions, and minimal physical activity. Sleep problems are very common in ESRD (up to 40%-80%) and range from insomnia and sleep apnea to restless legs syndrome. Indeed, poor sleep is itself a predictor of mortality and QOL [4].

Ongoing patient education and counseling could enhance adherence to treatments and thus improve QOL. Careful assessment of health-related QOL (HRQOL) can help provide medical management to optimize their health experience. HRQOL is recognized as an essential health outcome for studies evaluating the quality of health care, assessing the impact of illness, and analyzing cost-effectiveness. In addition, HRQOL has been shown to be clinically important in improving hemodialysis outcome in hemodialysis patients. With this background, the researcher is interested in evaluating the QOL among ESRD patients undergoing hemodialysis, in relation to all their domains, such as physical health, mental health, kidney disease problem and patient satisfaction [5].

Fatigue is a common symptom in dialysis patients and is associated with reduced health-related quality of life (HRQOL). Most dialysis patients experience fatigue and malaise after treatment. Within 5 hours after dialysis 80% of patients experience symptoms of fatigue. Symptoms of fatigue that occur after dialysis are referred to as post-dialysis fatigue (PDF). Unlike chronic fatigue syndrome, mental fatigue, and physical fatigue, the factors and mechanisms underlying PDF remain unclear. PDF symptoms and severity are assessed using several scales [6].

In PDF cases, patients' own subjective symptoms are studied and it is useful to use patient-based outcomes. However, in conventional PDF studies, the evaluation indices were not uniform. First, in studies assessing fatigue after hemodialysis based on “time,” “frequency,” and “intensity,” the reliability and validity of the scales were not examined. Second, recovery time is not an index that directly measures PDF but instead an indirect index that measures “time off dialysis”. Third, the fatigue scale does not measure actual PDF but rather the chronic fatigue experienced by dialysis patients. Elucidation of the relative determinants of PDF among dialysis treatment factors, nutritional status, and physical health factors would be extremely helpful. Reducing PDF will benefit both the physical health and prognosis of dialysis patients. However, international guidelines on the definition and optimal method of PDF measurement have not yet been established (6).

The causes of fatigue in ESRD are not understood but it appears that correction of anemia and physical activity actually improves the clinical condition of these patients. Despite improvements, it has been observed that the functional capacity of dialysis patients is not similar to that of the healthy population. One cause of reduced levels of physical activity is likely the dialysis procedure itself and, in particular, the length of the session. Thirty-three percent (33%) of dialysis patients reported feeling unwell in the first hours immediately after a dialysis session, with one in four showing severe to very severe post-session fatigue. Recognition of fatigue by nurses can be difficult given that recovery from this condition varies greatly between patients [7].

The success of chronic disease treatments largely depends on patient adherence to treatment regimens. According to the World Health Organization (WHO), socio-economic factors are among the most decisive factors influencing treatment adherence. An important feature of socioeconomic factors is social support. Access to social support may improve treatment outcomes among patients with chronic conditions. The results of many studies have shown that perceived social support contributes significantly to patients' physical and psychological well-being and their treatment. However, some other studies have shown that some supportive behaviors do not contribute to patient well-being and, on the contrary, can also harm it in some ways [8]. Social support has been considered an important factor in physical and psychological well-being. The literature has also shown its importance in how individuals cope with chronic illness, because in addition to loss of functionality, a chronic illness magnifies the stress of daily life and creates stress for all family members. Increased stress may promote patients' needs for social support, but may also affect those most able to provide support. The behavioral and emotional impact of social support on depression, which commonly accompanies chronic illness, manifests itself through several processes. On the one hand, social support can have a direct effect, promoting an effective, open and uncontrollable contact with the present moment, reducing the individual's tendency to question pain and physical limitation. On the other hand, social support can also promote the maintenance of one's important activities and enhance valued life activities [9].

The present research studies the social support and nursing care that dialysis patients receive, their fatigue levels as well as quality their lives. In addition, it is studied whether the social support and nursing care that patients receive affect the patients' levels of quality of life.

2. Method

2.1. Research design

This is a quantitative cross-sectional study including specific variables, like quality of life, social support and fatigue among patients as well as the satisfaction from the nurses.

2.2. Sample

The research population is considered to be all dialysis patients in Greece. Regarding the sample, 69 patients on hemodialysis participated in the research with most to have the disease 0-10 years. The majority of patients are men, aged 51-80 years, married with 1-2 children, with educational level up to that of Lyceum, who live in a city and receive an income of 500-1,500 euros. The criteria for entering or excluding the sample were considered: 1) the conduct of the session of hemodialysis, 2) the age over 18 years, 3) the Greek language and 4) diagnosed with end-stage CKD.

2.3. Questionnaires

For the needs of this research, 3 questionnaires were used: 1) "Multidimensional Scale of Perceived Social Support" [10], 2) Fatigue Assessment Scale (FAS) by Michielsen et al. [11] and 3) Missoula VITAS Quality of Life Index by Theofilou et al. [12]. It emerged from these questionnaires a questionnaire of 60 questions divided into 5 sections.

The 1st section includes 9 questions related to socio-demographic data of the patients, such as gender, age, marital status, number of children, education level, place of residence, employment, monthly income and years in hemodialysis.

The 2nd section refers to perceived social support which was measured according to the "Multidimensional Scale of Perceived Social Support" [10]. The questionnaire includes 12 questions on a 7-point Likert scale 1-7 (1= Strongly Disagree, 2=Strongly Disagree, 3=Disagree, 4=Neutral, 5=Agree, 6=Strongly agree, 7=Strongly agree), and 3 subsections of 4 questions about social support from others, from family and friends. The 3rd section refers to patient fatigue which was measured with the Fatigue Assessment Scale (FAS) questionnaire by Michielsen et al. [11]. The questionnaire includes 10 questions on a five-point Likert scale 1-5 (1= Never, 2=Sometimes, 3= Regularly, 4=Often, 5=Always) and 2 subsections of 5 questions about physical and mental fatigue.

The 4th section includes 16 questions about perceived quality of life of patients which was measured by the Missoula-VITAS Quality of Life questionnaire Index of Theofilou et al. [12]. The questionnaire includes 1 question about global quality of life five-point Likert scale 1-5 (1=Very poor, 2=Poor, 3=Average, 4=Good, 5=Very good) and 15 questions divided into 5 subsections of 3 of quality-of-life questions about symptoms, functioning, interpersonal relationships, wellness and spirituality. In each subsection the 1st question refers to evaluation (scale from -2 to +2), the 2nd to satisfaction (scale from -4 to 4) and the 3rd in importance (from 1 to 5).

The 5th section includes 13 questions on a five-point Likert scale from 1 to 5 (1= Not at all, 2=Little, 3=Moderate, 4=Quite a bit, 5=Too much), related to nursing care.

3. Results

Table 1 presents the demographics of the respondents. 73.9% (N=51) were men and 26.1% (N=18) were women. Regarding marital status, 66.7% (N=46) were married or cohabiting, 23.2% (N=16) single, 7.2% (N=5) widowed and 2.9% (N=2) from divorcees.

Regarding age, 34.8% (N=24) are 61-70 years old, 24.6% (N=17) 51-60, 14.5% (N=10) 71-80, 10 .1% (N=7) to 40, 10.1% (N=7) over 80 and 5.8% (N=4) 41-50 years old.

Table 1. Sociodemographic and clinical factors.

Factors		**N**	**f%)**
Gender	Male	51	73,9
	Female	18	26,1
Age	≤40	7	10,1
	41-50	4	5,8
	51-60	17	24,6
	61-70	24	34,8
	71-80	10	14,5
	>80	7	10,1
Family status	Single	16	23,2
	Married/roommate	46	66,7
	Divorced	2	2,9
	Widowed	5	7,2
Number of children	0	2	4,9
	1	9	22,0
	2	18	43,9
	3	6	14,6
	4	5	12,2
	6	1	2,4
Education	Απουσία εκπαίδευσης	3	4,3
	Δημοτικό	13	18,8
	Γυμνάσιο	9	13,0
	Λύκειο	25	36,2
	TEI	4	5,8
	AEI	11	15,9
	Μεταπτυχιακό	1	1,4
	Διδακτορικό	3	4,3
Residence	Town	48	69,6
	Village	18	26,1
	City	3	4,3
Work status	Public servant	9	13,0
	Private servant	2	2,9
	Student	1	1,4
	Freelancer	8	11,6
	Housewives	4	5,8
	Unemployed	7	10,1
	Pensioner	38	55,1
Monthly income	Without income	3	4,6
	500-1.000	29	44,6
	1.001-1.500	15	23,1
	1.501-2.000	12	18,5

	>2000	6	9,2
Years of dialysis	0-5	37	54,4
	6-10	18	26,5
	11-20	11	16,2
	>20	2	2,9

1st research question: What levels of perceived social support, fatigue, quality of life and nursing care do patients receive?

Given the 1-7 scale, very high levels of social support from family (M.O.=6.12 ± 1.33) and others (M.O.=6.07 ± 1.30) and high from friends emerged (M.O.=5.09 ± 1.50). Regarding fatigue, given the 1-5 scale, moderate levels of physical fatigue (M.O.=2.97 ± 0.95) and low levels of mental fatigue (M.O.=2.37 ± 0.91) were obtained.

Given the -30 to 30 scale, high levels of quality of life were observed in interpersonal relationships (M.O.=13.76 ± 12.40), moderate to high levels in symptoms (M.O.=7.00 ± 8.44) and spirituality (M.O.=6.24 ± 16.18), moderate in terms of functionality (M.O.=2.84 ± 13.51) and low in terms of well-being (M. O.=- 10.46 ± 14.20). Regarding the nursing care received by patients, given the scale of 1-5, the nursing care received by the patients was characterized as high (M.O.=4.36 ± 0.67).

2nd research question: To what extent does the social support and nursing care patients receive improve their quality of life?

Table 2 presents the results of the Spearman correlations between the factors of social support and nursing care with the factors of fatigue and quality of life. It turns out that "Quality of life-interpersonal relationships" was positively correlated with "Social support from others" (r=0.461, p<0.01), "Social support from family" (r=0.493, p<0.01) and "Social support from friends' (r=0.411, p<0.01). "Quality of life" was positively correlated with "Social support from others" (r=0.268, p<0.05) and "Social support from family" (r=0.276, p<0.05). "Global quality of life" was positively correlated with "Social support from others" (r=0.248, p<0.05) and "Social support from family" (r=0.253, p<0.05).

Table 2. Spearman correlation of social support and nursing care to quality of life.

Quality of life dimensions	**Social support - others**	**Social support - family**	**Social support - friends**	**Nursing care**
Symptoms	0,195	0,099	0,165	0,139
Function	0,195	0,182	0,125	0,123
Interpersonal relations	,461**	,493**	,411**	0,177
Well-being	0,007	-0,005	-0,145	0,088
Spirituality	0,103	0,121	0,107	0,114
Global QOL	,268*	,276*	0,214	0,148

*p<0,05, **p<0,01

4. Discussion

In the 1st research question, the levels of perceived social support, fatigue, quality of life and nursing care received by the patients were studied. Very high levels of social support from family and other people and high from friends were observed. The levels of physical fatigue were characterized as moderate and the mental levels low. Patients described their global quality of life as good. Deeper analysis revealed high levels of quality of life in interpersonal relationships, moderate to high in symptoms and spirituality, moderate in functioning, and low in well-being. Patients were very satisfied with the nursing care they received. Specifically, for social support from family, patients reported a lot that their family really tries to help them, that they get the emotional help and support they need from them, that they can discuss their problems with their family, and that they are willing help them make decisions.

Family support plays an essential role in the well-being of patients. Family support is the help of other family members who will provide physical and psychological assistance, such as attention, appreciation or helping the patient to accept his conditions. Effective and efficient family support is key to improving the well-being of patients receiving hemodialysis therapy. Family support in the form of emotions, expressed in behaviors such as listening and attention that make the person feel understood, and social support in everyday help, such as material and financial support or in daily activities, can improve their quality-of-life patient [13]. For social support from other people, patients very much agreed that there is a person near them when they need it, who is a real source of relief for them, who cares about their feelings and with whom they can share joys and sorrows. This is because most dialysis patients, when faced with a decline in interpersonal relationships, experience more difficulty managing their emotions. The absence of family and social support leads to an increased risk of death and reduced adherence to treatment, mainly due to depression [13].

Regarding social support from friends, patients reported that they have friends with whom they can share joys and sorrows, who really try to help them and discuss problems with them, and that they can lean on their friends in difficult times. According to patients' reports, they mainly want psychological, social and spiritual support, and the existence of a supportive circle of friends helps not only to cope with the psychological burden, but also leads to better results in relation to the management of the disease, symptoms, and even of hospitalization time, as it appears that support from friends helps patients adhere to the instructions of treating physicians [14]. Regarding physical fatigue, no difficulty was observed in the patients' concentration when performing an activity. In general, the levels of physical fatigue of the hemodialysis patients were observed to a moderate degree.

In the study by Kodama et al. [6], a high value of physical fatigue on the scale studied by the researchers revealed a reduced physical function. This result was similar to what has been reported in other studies, according to the authors, who believe that dialysis affects patients' physical function, even after adjusting for age and sex. A high value in the perception of fatigue was shown to be associated with worse CKD-related symptoms and life satisfaction. A previous study reported a relationship between physical function and a person's general health [6]. Regarding mental fatigue, this was observed to a small extent with patients stating that they rarely feel that they do not have clear thoughts and that they are mentally exhausted. According to Sakkas and Karatzaferi [15], the prevalence of general recorded mental fatigue in hemodialysis patients ranges from 30% to 80% depending on assessment tools and dialysis modality. Patients report a variety of psychological problems such as depression, irritability, mood swings and other problems arising from the severity of the disease and the chronicity of the problem. In addition, the majority of hemodialysis patients complain of "brain fog" and lethargy especially in the hours after hemodialysis, while one in two have very poor sleep quality and suffer from daily sleepiness. In addition, the hemodialysis process removes many small molecules involved in metabolism (glucose, amino acids, minerals, hormones, etc.) leaving the patient feeling "drained" and exhausted, with insufficient time to recover as the next dialysis takes place in less than 48 hours. Finally, the high rate of hospitalization, the predisposition to infection and the feeling of dependence on a dialysis machine, significantly reduce the level of motivation and the degree of self-esteem [15].

The levels of general well-being were characterized as low. Patients stated that it is important for them to be good about themselves, however they disagreed with the position that they are more satisfied with themselves now than they were before their illness. Since dialysis patients undergo hemodialysis care at least three times a week for several hours each time, and have a profoundly reduced quality of life, due to severe symptoms of fatigue, low appetite, pain, sleep disturbances, anxiety, nausea and restless legs, it's important for them to feel adequate to take care of themselves. It is also difficult for them to feel more satisfied with themselves now that the areas of life in which they can participate have been reduced [16]. Regarding nursing care, very high levels of satisfaction emerged. The patients stated that they are very satisfied with the behavior of the nursing staff and the feeling of security during the treatment process. In addition, they reported being very satisfied with the discretion of the nurses in matters concerning their health and the consistency with which they respond to their needs. Also, high satisfaction was observed with the technical skills (e.g. fistula puncture, venipuncture, administration of drugs), the psychological support from the nursing staff, the discretion with which each piece of information is given to them, the information they receive from the nursing staff, understanding their needs, respecting their views, encouraging questions and serving personal needs.

In the 2nd research question, it was investigated to what extent the social support and nursing care that the patients receive improves their quality of life. The results of the research revealed that participants with higher quality of life in interpersonal relationships receive more social support from others, family and friends. Also, patients with greater overall and global quality of life showed greater social support from others and family.

The results of the present research are generalizable to the patients of the artificial kidney unit of the Regional University Hospital of Rio. In addition, the results cannot be generalized for dialysis patients aged 51-80 years, with an education level up to high school, who live in a city and have been patients for up to 10 years, because the sample size was small and did not allow every case the application of parametric statistical tests that have greater power. Furthermore, the survey questionnaire referring to the quality of life showed acceptable but not satisfactory reliability. Finally, although social support was related to better overall quality of life, it showed low predictive power.

A future Pan-Hellenic research is proposed, comparative, in different Hospitals, public and private with stratified sampling, where the size of the sample will be determined by a mathematical formula from the size of the population. Furthermore, it is proposed to change the questionnaire that refers to the quality of life with a questionnaire that, according to previous researches, ranges at satisfactory levels of reliability (α>0.7). Finally, it is proposed to add additional factors that can improve the quality of life and reduce fatigue, according to the study of the theoretical framework, as those studied, namely nursing care and social support showed a low predictive power.

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