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Assessment of Symptoms and Quality of Life in Patients with Haemodialysis

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Abstract

Background: There is a growing body of evidence that haemodialysis symptoms was negatively correlated quality of life and increased morbidity and mortality rates, likely through a reduction in treatment adherence. The purpose of this study was to assess symptoms and quality of life in patients with haemodialysis.

Methods: This cross-sectional study included 170 randomly selected patients with haemodialysis who presented to the haemodialysis units in two state hospitals and a private hospital in Manisa, Turkey, between December 2017 and December 2018. A single interviewer collected all data using a socio-demographic form, the Dialysis Symptom Index (DSI) and the Nottingham Health Profile (NHP). Data were analysed using arithmetic averages, percentages and Pearson's correlation.

Results: The mean age of the participants was 52.32±11.69 (23-65), and most (%54.7) were males. Four symptoms were found to be most prevalent across all study samples: feeling tired or lack of energy (75.3%), decreased interest in sex (65.9%), difficulty becoming sexually aroused (65.3%) and feeling nervous (62.4%). It was found that the subscales scores of Nottingham Health Profile were 36.07±40.39 for energy level, 9.4±20.82 for pain, 29.53±30.44 for emotional reaction, 26.06±34.94 for sleep, 22.30±26.84 for social isolation and 30.74±31.67 for physical mobility, respectively. A positive correlation was defined between Dialysis Symptom Index and Nottingham Health Profile.

Conclusion: The results of this study indicated that patients receiving maintenance haemodialysis has been experienced several physical and emotional symptoms, the most prevalence and the most intense symptoms reported by our patients feeling tired or lack of energy, decreased interest in sex, difficulty becoming sexually aroused and feeling nervous and quality of life was lower among those with higher symptom severity.

Keywords: Haemodialysis; Chronic renal failure; Quality of life

Abbreviations: CKD: Chronic Kidney Disease; RRT: Renal Replacement Treatment; QOL: Quality of Life; DSI: Dialysis Symptom Index; NHP: Nottingham Health Profile.

Introduction

Based on different epidemiological data, chronic kidney disease (CKD) affects on average 8.2% of the population

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around the world [1]. The number of patients with chronic kidney disease undergoing haemodialysis in Turkey is growing. In Turkey, 73.660 patients receive renal replacement (RRT) treatment, of which about 77.3% are patients receiving haemodialysis [2,3]. Although RRT is life prolonging, patients on chronic dialysis have been shown to have significant symptoms and impaired quality of life (QOL). There is a growing body of evidence that haemodialysis symptoms was negatively correlated QOL [4-7], and increased morbidity and mortality rates [8], likely through a reduction in treatment adherence [9].

While there is little doubt that patients dependent on maintenance dialysis experience reduced physical and psychosocial well-being, considerably less is known about these health-related domains in patients with haemodialysis. Understanding the degree to which symptoms and impaired QOL affect patients with haemodialysis is important. Despite the importance of these symptoms on the quality of life of haemodialysis patients, treatable symptoms such as pain, nausea, fatigue, itching, dry mouth and feeling nervous could be under-recognized and its severity could be under-estimated by the health professionals [5,10].

Several studies demonstrated that symptoms including fatigue, lack of energy, pain, muscle cramps, difficulty with sleep, restless legs, and bone/joint pain affect half or more of patients undergoing haemodialysis [11-15]. Less research has been conducted investigating haemodialysis symptoms and quality of life in patients with haemodialysis [5,9,15,16]. As far as we know, there are no studies related to symptoms and quality of life among patients with haemodialysis in Turkey. In this study, the focus is on haemodialysis patients' experiences of dialysis symptoms and these symptoms affected on quality of life and well-being. We assume that well symptom management is positively related with quality of life of these patients and successful outcomes of their treatment and care. The aim of this study was to assess symptoms and quality of life in patients with haemodialysis.

Materials and Methods

Study design and participants

This descriptive and cross-sectional study included patients with haemodialysis who recruited from three dialysis centres situated in Manisa, Turkey, between December 2017 and December 2018. The sample size of the research was calculated using Epi Info version 6 (CDC, Atlanta, GA, USA) [17]. According to The Ministry of Health and Turkish Society of Nephrology Joint Report (2017) the prevalence of patients undergoing chronic haemodialysis population is 77.3% [3]. Odds ratio was used to determine the strength of association and was reported with 95% confidence interval, 5% deviation and 77% prevalence. From these, the minimum required sample size with a 95% confidence interval was calculated to be the minimum sample size was 166, and the maximum sample size was 303. During the study, about 420 patients undergoing chronic haemodialysis presented to three dialysis centres. Of these, through simple random sampling, 170 patients who agreed to participate were included in this study. The patients were selected according to the following criteria; that had been on haemodialysis for one and over years, HBV, HCV, HIV negative, and non-malignancy, between 18 and 65 years of age, able to speak and read Turkish, to be willing participant. The study purpose, procedural details, the participant's rights and potential benefits and risks of the study were explained and written consent forms were obtained from them.

Data collection

A patient identification form, Dialysis Symptom Index (DSI) and Nottingham Health Profile (NHP) were used the data gathering. In face-to-face interviews, socio-demographic form, DSI, and NHP were filled by the first researcher in the outpatient's clinics. Each interview took approximately 30 minutes.

Socio-demographic form: The socio-demographic form elicited personal information such as age, gender, marital status, and education status, and medical history, serum biochemical parameters.

The dialysis symptom index (DSI): This index was developed by Weisbord et al. (2004), for assessing physical and emotional symptoms and their severity [18]. The DSI contains 30 items, each of which targets a specific physical or emotional symptom. Patients enrolled in the study were asked to describe the presence (yes/no) of each symptom at any time during the previous 7 days. The severity of each reported symptom was assessed by asking patients to rate the degree to which the symptom was bothersome by using a 5-point Like rt scale (from 1= "not at all" to 5= "very much"). Two scores were generated from the DSI. First, an overall symptom burden score was formulated by totalling the number of symptoms reported as present. Second, a total symptom severity score was generated by summing the severity scores for each reported symptom, with a score of 0 for symptoms that were not reported as present. Using this scoring system, the minimum possible total severity score was 0 if none of the 30 symptoms was present and the maximum potential score was 150 if all of the 30 symptoms were reported and rated as “very much bothersome” (severity score of 5). The Turkish version of the DSI was tested by Önsöz and Usta-Yeşilbalkan (2013) who found the internal consistency (Cronbach’ alpha) to be 0.83 [19].

The Nottingham health profile (NHP): The Nottingham Health Profile (NHP) was developed to be used in epidemiological studies of health and disease. NHP is a widely used measure of perceived health status. The NHP is a self-administered questionnaire containing a first part with 38 statements belonging to six dimensions of health (Energy, Pain, Emotional Reactions, Sleep, Social Isolation, and Physical Mobility). The respondent answers "yes" if the statement adequately reflects his/her current status or feeling, or "no," otherwise. Each dimension is scored using weighted values which give a range of possible scores from zero (no problems at all) to 100 (presence of all problems within a dimension). Thus, 100 score indicate poor health and 0 score indicate good health. The Turkish version of the NHP was tested by Küçükdeveci et al. (2000) who found the internal consistency (Cronbach’ alpha) to be ranged between 0.56 and 0.83 [20].

Data analysis

Data were analyzed using SPSS version 15.0 (SPSS Inc., Chicago, IL, USA). Socio-demographic characteristics and scores of scales were examined using arithmetic averages, percentages and standard deviation. Pearson’s correlation analysis was used to examine the association between DSI and NHP variables. $P < 0.05$ was considered statistically significant.

Ethical issues

The study was conducted after obtaining approval from the Research Ethics Committee of Manisa Celal Bayar University, Manisa, Turkey (Ref. no.: 11/10/2017/20.478.486). Participants were informed about the study’s purpose, procedural details, their right and potential benefits and risks of the study. All participants were only included after they provided written consent forms.

Results

Socio-demographic and clinical characteristics of the sample

Table 1 shows socio-demographic characteristics of the sample. The mean age of the participants was 52.32±11.69 years (age range: 23–65 years), and the majority of them were males (54.7%). Table 2 shows clinical characteristics of the sample. Of the 170 patients who were interviewed, 48.2% had mean dialysis duration of 1–5 years.

Characteristics	n	%
Gender		
Female	77	45.3
Male	93	54.7
Marital status		
Married	121	71.2
Single	49	28.8
Educational status		
Literate	23	13.5
Primary school	132	77.7
High school	13	7.6
University	2	1.2
Vocation/job		
Yes	17	10.0
No	153	90.0
Insurance		
Yes	119	70.0
No	51	30.0
Income		
Low	112	65.9
Moderate	57	33.5
High	1	0.6

Table 1: Socio-demographic characteristics of the sample (n=170).

Further, Table 3 shows the serum biochemical parameters; 70.6% of participants had blood glucose <130 mg/dl and 65.9% of them had haemoglobin >11 g/dl. Four symptoms were found to be most prevalent across all study samples: feeling tired or lack of energy (75.3%), decreased interest in sex (65.9%), difficulty becoming sexually aroused (65.3%) and feeling nervous (62.4%) (Table 4).

Clinical characteristics	n	%
Years on haemodialysis		
1-5 years	82	48.2
6-10 years	56	32.9
More than 11 years	32	18.8
Causes of CKD#		
Diabetic nephropathy	44	25.9
Hypertensive nephropathy	37	21.8
Primary glomerular disease	39	22.9
Other urological diseases (stool, tumor, vesicoureteral reflux)	7	4.1
Unknown aetiology	27	15.9
Diabetic and hypertensive nephropathy	16	9.4
Interruption of dialysis sessions		
Yes	8	4.7
No	162	95.3

Note: #CKD=Chronic renal disease
Table 2: Clinical characteristics of the sample (n=170).1.

Variables	n	%
Blood glucose		
<130 mg/dl	120	70.6
>130 mg/dl	50	35.3
Haemoglobin		
<11 g/dl	58	34.1
>11 g/dl	112	65.9
Hematocrit		
<25	3	1.8
>25	167	98.2
Kt/V##		
<1,2 eKt/V	9	5.3
>1,2 eKt/V	161	94.7
URR###		
<%65	170	100
>%65		
Pre-dialysis blood urea nitrogen		
<55 mg/dl	170	100
Post-dialysis blood urea nitrogen		
>14 mg/dl	167	98.2
Pre-dialysis creatine		
>7,3mg/dl	98	57.6
Post-dialysis creatine		
<2,3mg/dl	75	44.1
Pre-dialysis potassium		
>5,5 mmol/L	50	29.4
Pos-tdialysis potassium		
<3 mmol/L	17	10

Calcium		
<8,4 mg/dl	59	34.7
>8,4 mg/dl	111	65.3
Phosphorus		
<5,5 mg/dl	130	76.5
>5,5 mg/dl	40	23.5
Blood pressure		
Systolic		
≤140 mmHg	141	82.9
>140 mmHg	29	17.1
Diastolic		
≤90 mmHg	159	93.5
>90 mmHg	11	6.5

Table 3: Laboratory variables of the sample (n=170).

Note: ##K=dialyzer clearance of urea; t=dialysis time; V=volume of distribution of urea, approximately equal to patient's total body water; ###URR= Urea reduction ratio; Grouping of parameters were conducted regarding recommendations of EBPG-Good Clinical Practice Guideline [21]

Symptoms	**n (%)**		**n (%)**									
			Not at all		**A little bit**		**Some-what**		**Quite a bit**		**Very much**	
Constipation	67	39	103	61	15	8.2	41	24	12	7.1	-	-
Nausea	65	38	105	62	18	11	40	24	7	4.1	-	-
Vomiting	46	27	124	73	12	7.1	29	17	5	2.9	-	-
Diarrhoea	29	17	141	83	8	4.7	20	12	1	0.6	-	-
Decreased appetite	67	39	103	61	27	16	23	14	15	8.8	2	1
Muscle cramps	99	58	71	42	12	7.1	63	37	22	13	2	1
Swelling in legs	37	22	133	78	14	8.2	16	9.4	5	2.9	2	1
Shortness of breath	54	32	116	68	21	12	19	11	14	8.2	-	-
Light-headedness or dizziness	89	52	81	48	31	18	47	28	11	6.5	-	-
Restless legs or difficulty keeping legs still	29	17	141	83	15	8.8	7	4.1	6	3.5	1	1
Numbness or tingling in feet	64	38	106	62	30	18	16	9.4	18	11	-	-
Feeling tired or lack of energy	128	75	42	25	36	21	42	25	47	28	3	2
Cough	50	29	120	71	19	11	22	13	9	5.3	-	-
Dry mouth	99	58	71	42	24	14	36	21	36	21	3	2
Bone or joint pain	83	49	87	51	22	13	24	14	35	21	2	1
Chest pain	33	19,4	137	81	12	7.1	16	9.4	4	2.4	1	1
Headache	75	44,1	95	56	22	13	37	22	16	9.4	-	-
Muscle soreness	29	17	141	83	11	6.5	12	7.1	6	3.5	-	-
Difficulty concentrating	66	39	104	61	30	18	27	16	9	5.3	-	-
Dry skin	60	35,3	110	65	32	19	10	5.9	17	10	1	1
Itching	84	49	86	51	21	12	29	17	33	19	1	1
Worrying	86	51	84	49	40	24	23	14	23	14	-	-
Feeling nervous	106	62	59	35	24	14	43	25	42	25	2	1
Feeling sad	84	49	86	51	36	21	38	22	9	5.3	1	1
Can't stay a sleep	56	33	114	67	13	7.6	11	6.5	32	19	-	-
Feeling irritable	78	46	92	54	37	22	21	12	19	11	1	1
Can't fall a sleep	63	37	107	63	18	11	15	8.8	29	17	1	1
Feel anxious	63	37	107	63	30	18	18	11	15	8.8	-	-
Decreased interest in sex	112	66	58	34	21	12	21	12	66	39	4	2
Difficulty becoming sexually aroused	111	65	64	38	17	10	21	12	64	38	4	2

Table 4: Severity of haemodialysis related symptoms of the sample (n=170).

It was found that the mean score of DSI was 54.97±14.40 (32-96); for NHP, the mean subscales score was 36.07±40.39 for energy level, 9.4±20.82 for pain, 29.53±30.44 for emotional reaction, 26.06±34.94 for sleep, 22.30±26.84 for social isolation and 30.74±31.67 for physical mobility, respectively. Table 5 summarizes the mean scores for each subscale of Nottingham Health Profile.

Nottingham Health Profile	Mean±SD¤	Min°°-Max°°°
Energy level	36.07±40.39	0-100
Pain	9.4±20.82	0-100
Emotional reaction	29.53±30.44	0-100
Sleep	26.06±34.94	0-100
Social isolation	22.30±26.84	0-100
Physical mobility	30.74±31.67	0-100

Table 5: The mean scores for each subscales of Nottingham Health Profile among the study sample (n=170).

Note: ¤SD=Standard deviation; °°Min=Minimum; °°°Max=Maximum

A significant positive correlation was found between the mean total DSI and NPH scores ($p < 0.05$), indicating that quality of life was lower among those with higher symptom severity (Table 6).

Nottingham Health Profile	Dialysis Symptom Index	
	r	p
Energy level	0.65	0.001**
Pain	0.46	0.001**
Emotional reaction	0.65	0.001**
Sleep	0.56	0.001**
Social isolation	0.39	0.001**
Physical mobility	0.59	0.001**

Note=*p<0.05; **p<0.01

Table 6: Relationship between Nottingham Health Profile Scores and Dialysis Symptom Index Score (n=170).

Discussion

Dialysis symptoms of haemodialysis patients have been variably reported in past studies [22-26]. It could be difficult to compare symptom prevalence across various studies as patients may be at various stages of renal deterioration or mode of treatment, accounting for the wide range in prevalence. Haemodialysis patients can typically have endured several complex symptoms for a prolonged period of time, and it would, therefore, be surprising if these symptoms did not adversely affect quality of life. The findings of the present study demonstrated that patients receiving maintenance haemodialysis has been experienced several physical and emotional symptoms, the most prevalence and the most intense symptoms reported by our patients feeling tired or lack of energy, decreased interest in sex, difficulty becoming sexually aroused and feeling nervous and quality of life was lower among those with higher symptom severity. These findings were similar to those by other researchers [5,7,9,16] which showed that high prevalence of symptoms significant impairments in health related quality of life. Chronic renal failure due to both disease and haemodialysis application; dietary and fluid restrictions, increased dependence, threat of death, changing roles in the family, economic problems, reduced social activities, physical, social, emotional and psychological changes that result from adversely affecting body image cause various symptoms to develop in patients [22-24,26].

In the current study, feeling tired or lack of energy (75.3%) was found as the most prevalent regardless of haemodialysis. This finding was similar to those by some researchers [11,13,14]. It was determined that relates to metabolic derangements, retained uremic toxins, comorbid medical conditions, physical rigors of haemodialysis therapy and emotional, social, and vocational impact of this chronic treatment [27-30].

In this study found that decreased interest in sex and difficulty becoming sexually aroused were the most severe and frequent symptoms in patients with haemodialysis. Similar findings have been reported in other studies involving varied cultural groups [5,6,31-33]. Contrary to several studies that was carried out in our country [14,34]. This finding can be explained that the first researcher was data collector who was the primary nurse of the patients. Patients regardless of cultural background tend not to report sexual symptoms unless the clinician specifically asks about it. Developing a standardised assessment method that helps patients to freely express their views on sensitive issues is needed.

In the current study we observed feeling nervous 62.4% of patients with haemodialysis. This finding was higher than those reported by other authors in descriptive studies [14,34]. The years on haemodialysis, the metabolic derangements that are common in patients, the economic and vocational impact of dialysis dependence likely contribute to feeling irritable, nervous and worry among these patients [16,35-39]. A qualitative study found that patients with haemodialysis developed a new identity and sense of self. This new and evolving emotional and psychological state indicated that patient's became cognisant of a new set of circumstances: an uncertain future, demands of illness, dependence of machinery, medication, and healthcare providers [40-42].

On the other hand feeling irritable, nervous and worry were described as symptoms of anxiety in another study [43-45]. It is associated with reduced treatment compliance, immune function and a poor nutritional status, which in turn leads to a negative view on life and might cause decrease well-being and quality of life among patients with haemodialysis [5,9,10,16,46-51]. Especially, functional disability is established every stage of renal insufficiency and it progressively deteriorates with on-going disease duration. In addition, functional disability could adversely affect individuals differently. The findings of the present study demonstrated that energy level and physical mobility was the most affected sub-dimension in the quality of life among patients with haemodialysis. Moreover, energy level and physical mobility was affected by severity of haemodialysis related symptoms. This finding is consistent with that of a previous study that investigated impact of fatigue, energy level, physical mobility on quality of life patients receiving maintenance haemodialysis [22,47,52-54]. In the current study found that haemodialysis related symptoms were associated with emotional reaction and impaired quality of life. The patients can feel their life has been limited to going to and from the unit, shows their dissatisfaction because they do not feel independent anymore, and because they do not engage in activities that they would like to. The duration of the sessions acts cumulatively by limiting the daily routine of the patient and her/his family and by making the emotional burden even heavier [37-39,55]. Sleep is also one of the factors related to quality of life. In the present study, sleep was affected by severity of haemodialysis related symptoms. This finding linear with that of previous studies that investigated sleep quality and sleep impairment among patients with haemodialysis [56-59].

Renal insufficiency and especially haemodialysis can influence a person as an individual and also as a member of the family and social environment. The difficulty to be efficient as a spouse, a parent, a partner, a professional is due to the physical and emotional consequences of haemodialysis [39,55,60,61]. In the present study showed similar results were obtained by other researchers [39,55,60-62]. That proved that patients receiving haemodialysis have a worse social life and social well-being was adversely affected by severity of haemodialysis related symptoms [10,15,16,30,63].

Pain can be due to co morbid conditions, renal insufficiency or the haemodialysis related symptoms among patients receiving haemodialysis. In our study, the prevalence of pain was similar to the past studies [4,64-66] but was not among the most intense symptoms. On the other hand, dialysis symptoms negatively affected pain, which is a sub - dimension of NHP. Several studies indicated that pain negatively affected haemodialysis patients' physical competence, mental status and social activities and associated with impaired quality of life [10,16,30,35,38,41,45].

Conclusion

There are limitations to this study. The first, our patient population was relatively small, which may decrease the generalizability of our findings. The second, we excluded patients with severe co morbidities such as HBV, HCV, HIV positive, and malignancy. Nevertheless, the current study stated that the importance of haemodialysis symptoms in the improvement of quality of life. The results of this study show that significant correlation between prevalent and severity of symptoms and quality of life suggests that interventions to alleviate these symptoms may provide a potential opportunity to improve quality of life. A multidisciplinary team approach to treat the symptoms could be beneficial to improve the quality of life and overall care of the haemodialysis patients.

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