

# The Effect of Illness Perception on Hopelessness Level of Patients Receiving Hemodialysis

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## Abstract

**Objective:** The study was conducted as a descriptive study to determine the effect of illness perception on the level of hopelessness in patients receiving hemodialysis.

**Materials and Methods:** The study was conducted with 281 patients who agreed to participate in the study in İnönü University Turgut Özal Medical Centre, Malatya State Hospital, Beydağı State Hospital, Malatya Park Hospital and Private FMC Malatya Dialysis Centre, in all state and private dialysis centers in Malatya between July 2014 and January 2017. Data were collected using the Patient Information Form, the Beck Hopelessness Scale, and the Illness Perception Questionnaire. Number, mean, percent, Kruskal–Wallis variance analysis, independent groups t-test, and correlation analysis were used to evaluate the data.

**Results:** The hopelessness levels of patients receiving hemodialysis were found to be high. Illness perception and almost all sub-dimensions were found to affect hopelessness.

**Conclusions:** It is suggested that nurses should take into account the relationship between illness perception and hopelessness level; trainings for disease perception should be given; and psychosocial support should be provided for patients receiving hemodialysis who are hopeless.

**Keywords:** Hemodialysis, illness perception, hopelessness

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## INTRODUCTION

End-stage renal disease (ESRD) is a life-threatening disease that causes progressive and irreversible loss of kidney function (1). The incidence and prevalence of ESRD is increasing worldwide (2, 3). According to the Ministry of Health of the Republic of Turkey and the Turkish Society of Nephrology Joint Report, by the end of 2016, number of patients receiving hemodialysis (HD) regular in the program in Turkey number is 56,687 (76.1%). Turkey is among the top ten countries in the world with the highest ESRD prevalence that require renal replacement (3).

ESRD is a chronic disease that needs to be adapted to the side effects of the disease and treatment. This disease negatively affects people's daily life and independence. Some patients are completely negative about their illness and indicated that their freedom is limited. The negative perception of the disease leads to more intense psychological problems such as hopelessness and depression (4). On the other hand, the positive perception of the disease in patients with chronic kidney failure (CRF) positively affects self-esteem and autonomy (5). It is also reported that illness perception is an important factor to understand the quality of life of patients receiving dialysis (6, 7).



How the patient with ESRD perceives his illness affects the balance and harmony of the individual at a considerable level, depending on the adversities of his/her illness (8). Therefore, how the illness is perceived is an important influence on the course of the disease and on the initiatives to be planned. Yildirim et al. (9) have determined that the anxiety or depression risk increases in patients receiving HD with negative illness perception. Studies have shown positive perception of illness among the patients positively affects treatment compliance, participation in the treatment process, and illness course (10, 11).

Some patients interpret their illness completely negative and restrict their daily activities. Perceptions of patients' illnesses as totally negative cause feelings of hopelessness to be felt more (4). Bicer and Bayat (12), Erdem et al. (13), and Tan et al. (14) found that patients who underwent HD treatment experienced hopelessness.

**258** It is important for patients with ESRD to have meaning for their illness and to consider hopelessness conditions in to be able to fully benefit from the treatment process. Mollaoğlu et al. (15) found that there was a positive relationship between illness perception and hopelessness. Some patients negatively perceive their illness, which makes them hopeless. The way in which the disease is perceived can increase or decrease the coping power of the patients (4).

Nurses play a key role in illnesses, dialysis machines, and their adaptation in lives of patients with HD. Anxiety, depression, and hopelessness occur in patients who undergo HD treatment for a long time. To reduce this void, the nurses must be fully informed to take precautions before complications occur, as well as HD principles. The self-confidence of the nurse in this regard and the patient's understanding of this skill of the nurse improve the harmony between the patient and the nurse (15).

In this context, the determination of illness perception and hopelessness levels of patients receiving HD bear great importance for the prognosis of these patients. When in the ESRD, incidence of the disease in Turkey and world is considered high, the lack of studies done in comparison to this ratio is noteworthy. Based on this information, it can be said that there is a need for studies that evaluate illness perception, determine the levels of hopelessness, and reveal the relationship between the illness perception and hopelessness levels of the individuals who undergo HD treatment.

The research was carried out to determine the effect of illness perception on the hopelessness level of patients receiving HD.

## MATERIALS and METHODS

This research was a descriptive correlational study. Study was conducted in all dialysis center in İnönü University Turgut Özal Medical Centre, Malatya State Hospital, Beydağı State Hospital, Malatya Park Hospital and Private FMC Malatya Dialysis Centre, in all state and private dialysis centers in Malatya between July

2014 and January 2017. The study universe consisted of 350 adult patients who received HD treatment in a city located in eastern Turkey. In the sample of the study, the entire universe was sampled without going to any sampling method. Among them, 25 patients who refused to participate in the study, 29 patients who were separated from HD units, and 15 patients who had communication problems were excluded from the study. The study was completed by reaching 80% of the universe with 281 patients. Informed consent was obtained from all participants included in the study.

Between July 2014 and February 2015, data were collected by face-to-face interview conducted by the researcher. The process of collecting the data was completed in HD-applied lounges, which are an equal environment for all, and while the treatment was ongoing. Each interview lasted 20–25 min on average.

The data were collected using the Patient Information Form, the Beck Hopelessness Scale (BHS), and the Illness Perception Questionnaire (IPQ).

**Patient Information Form:** The form prepared by the researcher consisted of nine questions about the descriptive characteristics of the patients and the health story.

**Beck Hopelessness Scale:** BHS developed by Beck and colleagues in 1974 consisting of 20 items each scored between 0 and 1 (16). In 11 items "yes" choice yields 1 point, and in 9 items "no" choice yields 1 point. The range of scores to be obtained from the scale is 0–20. Seber and colleagues (17) conducted validity and reliability study of Turkish scale. The scale consists of 20 items. Of these items, in 9 items "no" choice yields 1 point and in 11 items "yes" choice yields 1 point. The high score indicates high hopelessness of the individual (16, 17). There are three sub-dimensions of BHS as motivation loss, expectations about the future, and hope. Cronbach's alpha values of the scale were found between 0.72 and 0.78 (17). In this study, Cronbach's alpha values were found to be 0.69-0.77.

**Illness Perception Questionnaire:** IPQ was developed by Weinmann (18) in 1996 and was revised in 2002 by Moss-Morris et al. (19). Armay et al. (20) conducted validity and reliability study of Turkish scale in 2007. The scale is Likert-type. IPQ consists of three dimensions: type of illness/symptom, views on illness, dimensions of cause of illness. The illness symptom dimension includes 14 common illness symptoms. For each of these symptom, the person is first asked "whether he or she has lived since the onset of the illness," and then "whether or not he or she has seen this symptom related to the illness". This dimension is arranged so that for each symptom, two questions will be answered in the form of yes or no. The sum of the "yes" answers in the second question constitute the result about the evaluation of the illness symptom (19, 20). The dimension of the views about the illness consists of 38 items and contains seven subscales. These include duration (acute/chronic), out-

comes, personal control, cure control, illness understanding, duration (cyclical), and emotional representations. High scores on personal control, cure control, understanding of the illness sub-dimensions, and personal comprehension of the situation indicate the positive beliefs about the control of the illness and its treatment. High score on emotional representation indicates that person has high negative feelings about the illness. The dimension of the cause of illness consists of 18 items, including possible causes of the disease, and includes four subscales. These include psychological referrals, risk factors, immunity, accident, or luck. The Cronbach alpha values were found to be 0.651-0.935 (20). In this study, the Cronbach alpha values were found to be 0.81-0.97 in this study.

The illness perception of individuals receiving HD treatment is the independent variable of the study.

Hopelessness levels of individuals receiving HD treatment are the dependent variables of the study.

### Statistical Analysis

In the statistical evaluation of the data, the Statistical Package for Social Sciences (SPSS) 17.0 package program (IBM Corp.; Armonk, NY, USA) was used. Number, mean, percent, Kruskal-Wallis variance analysis, independent groups t-test, correlation analysis were used in the statistical evaluation of the data obtained as a result of the study. The results were evaluated at 95% confidence interval,  $p < 0.05$  significance level.

The research was accepted as a master's thesis by the Institute of Health Sciences at İnönü University in January 2017 with the name of "The Effect of Illness Perception on Hemodialysis Patients' Hopelessness Level." The Institutional Review Board of İnönü University (no. 2015-10/7) granted ethical approval of the study. The study purposes were explained to the patients, who consented orally to participate.

### RESULTS

Of the patients, 59.1% were 60 years old or above (mean  $60.38 \pm 12.48$  years), 50.5% were male, 72.6% were married, 46.3% were primary school graduates, 57.3% were not working, 40.9% of them had five children and above, 50.9% of them had moderate income, 36.3% of patients had CRF for 1-5 years, and 50.5% of them had HD treatment for 1-5 years (Table 1).

The mean scores of BHS of the patients were  $13.70 \pm 6.82$ . The highest scores patients receive from the illness perception scale was determined as: in the illness symptom as  $9.86 \pm 2.43$ , in the views about illness for dimension duration (acute/chronic) score as  $25.91 \pm 4.66$ , and in causes of illness dimension, the risk factors' score as  $14.00 \pm 3.69$  (Table 2).

Power loss was the most common symptom (85.8%) of the patients, and this symptom was symptom attributed to illness (85.8%) (Table 3).

**Table 1.** Patient Introductory Characteristics (n=281)

Introductory Characteristics	Classification	n	%
Age (Mean $\pm$ SD)= 60.38 $\pm$ 12.48	Age 19-39	20	7.1
	Age 40-59	95	33.8
	Age 60 and above	166	59.1
Gender	Female	139	49.5
	Male	142	50.5
Marital Status	Married	204	72.6
	Single	77	27.4
Education Level	Illiterate	116	41.3
	Primary	130	46.3
	High school	21	7.5
	University and above	14	5.0
Working Status	Not working	161	57.3
	Officer	97	34.5
	Self-employment	23	8.2
Children	None	31	11.0
	1-2	50	17.8
	3-4 children	85	30.2
	5 and above	115	40.9
Income	Good	54	19.2
	Medium	143	50.9
	Bad	84	29.9
Illness Time	1-5 years	102	36.3
	6-10 years	85	30.2
	11 years and above	94	33.5
Hemodialysis Time	1-5 years	142	50.5
	6-10 years	91	32.4
	11 years and above	48	17.1

Patients' HAQ disease symptoms, duration (acute/chronic), results, emotional representations, psychological factors, in immunity statistically positive correlation was detected. A statistically significant negative correlation was observed between the dimension of personal control, treatment control and understanding of the disease, and all of the subscales of the BHS scale ( $p < 0.05$ ). Patients' hopelessness scores increased as the mean score of the illness symptom increased. It was found that the level of hopelessness decreased as the patients increased their control over the disease, increased their beliefs that they could control their treatment, and increased their understanding of their illness (Table 4).

### DISCUSSION

The findings of this study conducted to determine the effect of illness perception on the level of hopelessness in patients receiving HD were discussed in the light of the literature.

**Table 2.** Distribution of Beck Hopelessness Scale and Illness Perception Score Averages of Patients (n=281)

	M±SD	Min-Max
<b>Beck Hopelessness Scale Total Score</b>	13.70±6.82	0-20
Emotions About Future	3.54±1.97	0-5
Motivation Loss	5.46±2.80	0-8
Hope	4.71±2.30	0-7
<b>Illness Symptom</b>	9.86±2.43	1-14
<b>View About Illness</b>		
Time (Acute / Chronic)	25.91±4.66	10-26
Outcomes	23.14±3.62	6-28
Personal Control	17.57±5.89	6-26
Cure Control	14.59±4.28	5-25
Illness Understanding	14.00±5.68	5-22
Duration (Cyclical)	14.81±2.80	4-20
Emotional Representation	25.42±5.62	6-30
<b>Causes of Illness</b>		
Psychological Factors	12.11±3.92	6-26
Risk Factors	14.00±3.69	7-26
Immunity	6.54±2.23	3-15
Accident/Luck	5.23±1.25	2-10

In the study, it was determined that patients' mean score of BHS was 13.70±6.82, and the mean score of motivation loss subscale was higher than the other subscales (Table 2). In both studies conducted by Erdem et al. (13) and Tan et al. (14), the mean hopelessness score of the patients who underwent HD treatment was determined as 8.8±5.1. Biçer and Bayat found that the mean hopelessness score of patients receiving HD was 8.2±5.1 (12). Our research results are similar to these studies. Patients who experience many physical, psychological, social, and economic problems because of HD treatment may experience hopelessness.

When the views of the patients receiving HD about the illness were examined, it was determined that the mean score of the duration (acute/chronic) subscale was the highest, followed by the mean score of the emotional representation subscale. Moreover, it was determined that the subscale of understanding the illness had the lowest average scores (Table 2). Karabulutlu and Okanlı (21) and Krespi and Kuntuz (22) also found that while the mean scores of the subscales of duration (acute/chronic) and emotional scales were high, the scores of the subscale of understanding the illness were the lowest. The results of these studies are similar to our findings. The low scores of un-

**Table 3.** Score Distributions of Disease Symptoms Dimension of Illness Perception Questionnaire (n=281)

Symptoms	I have experienced this symptom since the beginning of my illness	This symptom is related to my illness
	n (%)	n (%)
Power loss	241 (85.8)	241 (85.8)
Fatigue	236 (84.0)	236 (84.0)
Feeling of dizziness	158 (56.2)	158 (56.2)
Sleep difficulties	155 (55.4)	147 (52.3)
Pain	148 (52.7)	137 (48.8)
Weight loss	132 (47.0)	132 (47.0)
Joint stiffness	145 (51.6)	128 (45.6)
Headaches	136 (48.4)	126 (44.8)
Nausea	95 (33.8)	95 (33.8)
Stomach burns	110 (39.1)	92 (32.7)
Difficulty in breathing	105 (37.4)	78 (27.8)
Burning in the eyes	88 (31.3)	45 (16.0)
Burning in the throat	48 (17.1)	39 (13.9)
Intense noisily	29 (10.3)	18 (6.14)

derstanding illness and high score of emotional representations seen in the study indicate the need of support for the patients to understand their illnesses and to cope with the emotions they have experienced with the illness (21). For the duration (acute/chronic) subscale has a high average score, it can be considered that the majority of patients perceived ESRD as a chronic disease.

The patients who participated in the study indicated that risk factors and psychological references are the causes of their illness (Table 2). According to the results of the study by Krespi et al. (23), they found that patients showed psychological factors and risk factors as the most frequent cause of the disease. The results of this study are similar to those in the literature (21, 22). Patients receiving HD relate the causes of illness to stress, distress, and anxiety as well as hereditary eating habits, poor medical care, self-behavior, aging, smoking, alcohol abuse (23).

In the study, it was determined that patients receiving HD experienced the most frequent symptoms of the illness since the onset of the illness; and that the symptoms related to illness were power loss and fatigue. In addition, symptoms such as loss of power, fatigue, and dizziness were in the first three ranks of patients have been associated with the disease (Table 3). Karabulutlu and Okanlı (21) and Krespi et al. (23) found that patients receiving HD indicated that among all the symptoms of illness in

**Table 4.** Relationship between Illness Perception and Beck Hopelessness Scale Score Averages

		Hopelessness Total Score	Emotions About Future	Motivation Loss	Hope
Illness Symptom	r	0.265**	0.272**	0.267**	0.226**
	p	0.000	0.000	0.000	0.000
Duration (Acute/Chronic)	r	0.530**	0.545**	0.489**	0.507**
	p	0.000	0.000	0.000	0.000
Outcomes	r	0.184**	0.210**	0.178**	0.148*
	p	0.002	0.000	0.003	0.013
Personal Control	r	-0.424**	-0.431**	-0.386**	-0.416**
	p	0.000	0.000	0.000	0.000
Cure Control	r	-0.541**	-0.531**	-0.501**	-0.537**
	p	0.000	0.000	0.000	0.000
Understanding Illness	r	-0.171**	-0.171**	-0.160**	-0.166**
	p	0.004	0.004	0.007	0.005
Duration (Cyclical)	r	-0.073	-0.052	-0.063	-0.094
	p	0.225	0.387	0.292	0.115
Emotional Representations	r	0.280**	0.267**	0.262**	0.283**
	p	0.000	0.000	0.000	0.000
Psychological Factors	r	0.129*	0.110	0.156**	0.098
	p	0.031	0.067	0.009	0.101
Risk Factors	r	0.081	0.099	0.068	0.071
	p	0.178	0.098	0.256	0.235
Immunity	r	0.126*	0.114	0.129*	0.119*
	p	0.035	0.056	0.030	0.047
Accident or Luck	r	-0.021	-0.016	-0.020	-0.025
	p	0.725	0.793	0.740	0.680

\*p&lt;0.05 \*\* p&lt;0.001

the disease description section, they experienced mostly loss of strength and fatigue symptoms. Cardenas and Kutner (24) and Bossola et al. (25) found that the most of the patients receiving HD complained about fatigue. Our research findings are parallel with the results of these studies. HD sessions are considered the most effective factors in patients' complaints of power loss and fatigue symptom.

In the study, it was found that as the mean score of patients' illness symptoms scores increased, the hopelessness scores also increased; increased control over the disease, increased beliefs that they could control their treatment, and increased levels of understanding their illness, the levels of hopelessness also decreased. Mollaoğlu et al. (15), in their study, determined that there was a positive relationship between the illness per-

ception and hopelessness. Similarly, Ibrahim et al. (4) and Kim and Evangelista (15) have found a significant positive relationship between illness perception and hopelessness level. Some patients perceive their illness as negative, which causes them to be unhappy and to live lives that are more depressed. The way in which the illness is perceived can increase or decrease the coping power of the patients. Therefore, it is considered that the patients who perceive their illness as a negative situation are more hopeless.

## CONCLUSION

Anxiety, depression, and hopelessness occur in patients who undergo HD treatment for a long time. To reduce this void, the nurses must be fully informed to take precautions before complications occur, as well as HD principles. The self-confidence of



the nurse in this regard and the patient's understanding of this skill of the nurse improve the harmony between the patient and the nurse.

This study does not have any limitations. The results of the research can be generalized to the population with similar characteristics.

**Ethics Committee Approval:** Ethics Committee approval was received for this study from the Ethics Committee of İnönü University (no. 2015-10/7).

**Informed Consent:** Informed consent was obtained from all participants included in the study.

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