

# The Relationship Between Illness Perception and Disability in Hemodialysis Patients

## Hemodiyaliz Hastalarında Hastalık Algısı ve Yeti Yitimi İlişkisi

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**ABSTRACT Objective:** End-stage renal disease is a chronic situation requiring life-long dialysis or kidney transplantation. The objective of this study is to determine the relationship between illness perception and disability in hemodialysis due to chronic kidney failure. **Material and Methods:** This is a descriptive study. The sample group is comprised of 86 hemodialysis patients who were in compliance with the study criteria and who could be reached throughout the duration of the study. Study data were collected using Questionnaire on Sociodemographic and Illness Characteristics, Illness Perception Questionnaire and Brief Disability Questionnaire. Necessary permissions were obtained beforehand. Data collection was carried out between September, 2 - November, 29, 2013. The data were analyzed by using percentage, t test, Kruskal Wallis Variance analysis, Mann Whitney-U test, and pearson correlation analysis. **Results:** According to the results of the study, it was found that 53.5% of the patients were female, 77.9% were married. As for other demographic data, 73.2% of the patients had primary education or were illiterate, 86.0% were covered under social insurance. Participants with a high level of disability also had high perceptions of consequences ( $r=0.425$ ,  $p=0.000$ ), timeline ( $r=0.145$ ,  $p=0.184$ ), emotional representations ( $r=0.312$ ,  $p=0.003$ ), and psychological references ( $r=0.297$ ,  $p=0.006$ ); they cannot explain ( $r=-0.210$ ,  $p=0.022$ ) or control the illness ( $r=-0.288$ ,  $p=0.007$ ) and they also had a high illness identity perception ( $r=0.339$ ,  $p=0.001$ ). **Conclusion:** Relationship was identified between the patients' negative perception of illness and disability.

**Key Words:** Hemodialysis units, hospital; outpatients

**ÖZET Amaç:** Kronik bir hastalık olan son dönem böbrek hastalığı, tedavi seçenekleri yaşam boyu diyaliz ya da böbrek transplantasyonu olan bir hastalıktır. Çalışmanın amacı kronik böbrek yetmezliği nedeniyle hemodiyaliz uygulanan hastaların hastalık algısı düzeyi ile yeti yitimi arasındaki ilişkinin belirlenmesidir. **Gereç ve Yöntemler:** Çalışma tanımlayıcı niteliktedir. Çalışmaya dahil edilme kriterlerine uyan ve çalışma süresince ulaşılabilen 86 hemodiyaliz hastası çalışmanın örneklemini oluşturmuştur. Veriler Sosyo-demografik ve Hastalık Özelliklerine İlişkin Anket Formu, Hastalık Algısı Ölçeği ve Kısa Yeti Yitimi Anketi kullanılarak gerekli izinler alındıktan sonra 2 Eylül- 29 Kasım 2013 tarihleri arasında toplanmıştır. Verilerin analizinde yüzdelik, t testi, Kruskal Wallis Varyans analizi, Mann Whitney-U testi, pearson korelasyon analizi kullanılmıştır. **Bulgular:** Araştırma kapsamına alınan hastaların %53,5'i kadın ve %77,9'u evliydi. Hastaların %30,2'si okur yazar değil, %43,0'i ilköğretim mezunu olup, %86,0'ının sosyal güvencesi vardı. Yeti yitimi derecesi yüksek olan hastaların, sonuçlar ( $r=0,425$ ,  $p=0,000$ ), süre (akut/kronik) ( $r=0,145$ ,  $p=0,184$ ), duygusal temsiller ( $r=0,312$ ,  $p=0,003$ ), psikolojik atıflar algısının yüksek olduğu ( $r=0,297$ ,  $p=0,006$ ), hastalığını anlamlandıramadığı ( $r=-0,210$ ,  $p=0,022$ ) ve hastalığı kontrol edemediği ( $r=-0,288$ ,  $p=0,007$ ), ayrıca hastalık tipi algısının ( $r=0,339$ ,  $p=0,001$ ) yüksek olduğu saptanmıştır. **Sonuç:** Hastaların hastalıklarını olumsuz algılamaları ile yeti yitimi arasında ilişki olduğu görülmüştür.

**Anahtar Kelimeler:** Hemodiyaliz birimi, hastane; ayaktan hastalar

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End-stage renal disease (ESRD) is a chronic situation requiring life-long dialysis or kidney transplantation.<sup>1,2</sup> The most common treatment of renal diseases is hemodialysis (HD).<sup>3</sup> According to the 2005 data of Turkish Society of Nephrology, the number of chronic kidney failure (CKF) patients receiving HD treatment was 28.507 in total but in 2010, this number reached 49.505.<sup>3,4</sup>

Hemodialysis treatment is an eminent method of treatment for prolonging the life span of renal patients. However, HD patients might encounter other challenges such as lowered work capacity, decreased physical activity and domestic problems. The necessity for HD patients to receive treatment at certain times and days causes them to be dependent on the machine, hospital and health care personnel.<sup>2,5</sup>

Disability is defined as any restriction or loss of ability to perform an activity in the manner or extent regarded normal for an individual. It can be either temporary or permanent.<sup>6,7</sup> It is also reported that disability is more common when accompanied by a chronic physical disease or mental disorder in comparison with chronic physical disease only.<sup>8</sup> Disease related disabilities can also bring about psychosocial disability.<sup>9</sup> In recently studies detected high total disability score patients with ESRD.<sup>7,10</sup>

Perception of illness is a reflection of the individuals' beliefs and expectations regarding any disease or symptom.<sup>11</sup> It is based on Leventhal's 'self-regulatory model' (SRM).<sup>12,13</sup> The SRM outlines the process in which physical sensations and illnesses are stimuli for patients in constructing a model encompassing a cognitive and an emotional representation of those stimuli and their meaning (Figure 1).<sup>14,15</sup> According to the model, individuals make up mental diagrams regarding the disease and other threatening situations in the light of concrete and abstract knowledge provided for them. Such cognitive models of patients also include beliefs related with treatment and control of the situation.<sup>2,12-16</sup>

Leventhal's model has been tested in a range of populations, including individuals at risk for venous thrombosis and rheumatoid arthritis, diabetes

mellitus, hypertension, cancer.<sup>16-20</sup> Results from these studies indicate that positive beliefs in controllability and curability of the illness are positively associated with well-being.

Negative perception of the illness leads to intensive unhappiness and depression along with an increased risk of mortality.<sup>21,22</sup> On the other hand, it is pointed out that positive perception of ESRD also affects self-esteem and autonomy in a positive way.<sup>23</sup>

Due to the reasons above, nurses need to assess perception of illness reflecting its individual cognitive and emotional representations.<sup>24</sup> Thus, nurses can help HD patients acquire problem-solving skills so that they learn how to manage themselves, cope with the emotional status due to the chronic disease.

Although positive perception of the illness might reduce disability in patients with ESRD, the literature offers so limited findings regarding the relationship between perception of illness and disability for HD patients. Once the correlation between perception of illness and disability in HD patients is identified from collected data; scientific data will be obtained to improve nursing practices performed in HD units at the same time.

## RESEARCH QUESTIONS

1. What are the patient characteristics that affect the illness perception in HD patients?
2. What are the patient characteristics that affect the disability in HD patients?
3. What is the relationship between the level of illness perception and disability in HD patients?

## MATERIAL AND METHODS

### DESIGN AND SAMPLE

This is a descriptive study. Study population is comprised of 158 HD patients receiving HD treatment (at least for 6 months), 123 of whom are hospitalized in the HD unit of Kilis State Hospital (KSH) and 35 of whom are in the same unit at Tunceli State Hospital (TSH).

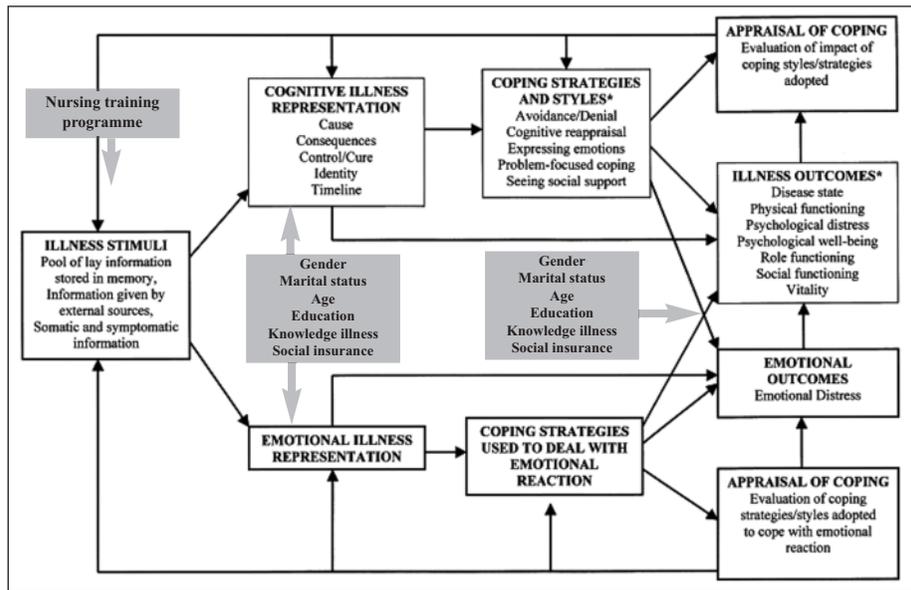


FIGURE 1: Schematic representation of Leventhal et al.'s (1980) Common Sense Model of Illness Representation.<sup>14</sup>

The numbers of patients that did not participate in the study from KSH and TSH were 13 and 10 respectively and the reason for this was that these patients were not at the hospital at that time. Also some patients were not included in the study due to incompliance with study criteria (TSH, n=7; KSH, n=42). As a consequence, the study group was comprised of 86 HD patients actively receiving treatment in the HD units between 2 September-29 November 2013.

### ETHICAL CONSIDERATION

Written permissions were obtained for this study from the ethics committee (No:17.09.2013/311) of Gaziantep University Faculty of Medicine, the hospital managements of the provinces where the study was conducted and the Provincial Health Directorate. All participants provided written informed consent.

### DATA COLLECTION

Data collection tools used in this study were Questionnaire on Socio-demographic and Illness Characteristics containing 13 questions, The Illness Perception Questionnaire (IPQ) and Brief Disability Questionnaire (BDQ). The patients were asked to fill the IPQ and BDQ questionnaires following HD sessions since they had less symptoms regard-

ing the illness and were feeling relatively better. The investigator collected data through face-to-face interviews during the data collection period. Implementation period of data collection instruments lasted 30-40 minutes.

### SOCIODEMOGRAPHIC AND ILLNESS CHARACTERISTICS FORM

This form was developed by researchers by referring to the literature.<sup>2,7,21</sup> Sociodemographic data were collected by means of seven questions about age, gender, marital status, education, working status, place of living and social insurance. Data regarding the illness were collected via six questions investigating duration of CKF and HD, frequency of HD, cause of CKF, knowledge illness, and whether or not there is somebody assisting their health care.

### Illness Perception Questionnaire (IPQ)

The scale was developed by Weinmann in 1996 and revised by Moss-Morris et al. in 2002<sup>25,26</sup>. The reliability and validity studies of the Turkish adaptation of the revised questionnaire were carried out by Kocaman et al.<sup>27</sup>

The IPQ was developed mainly for quantitative measurement on five areas of illness representation which are; identity, timeline, cause, serious

consequences and treatability/controllability. The questionnaire includes three parts; perception, symptoms (identity) and causes.<sup>27</sup>

The IPQ consists of such parts as illness identity (symptoms), views about the illness and causes of the illness. The first part covers 14 common symptoms of the illness. For each of the symptoms, respondents are first asked "Have you been experiencing this symptom since the onset of the illness?", followed by "Do you think this symptom is associated with your illness?". This part was arranged in a way as to allow a yes/no answer for both questions under each symptom. Illness identity is determined according to total scores of positive responses for question two. High scores of illness identity imply the strong belief that there are a high number of symptoms involved in the illness.

**Views about the illness (perception):** The perception part consists of 38 questions of 5-item Likert type (from "strongly disagree" to "strongly agree") and seven subscales:

**Timeline (acute/chronic):** The patients are asked about perceptions on timeline of the illness classifying it as acute, chronic and cyclical.

**Consequences:** The patients are asked about beliefs in potential effects of the illness on severity as well as the physical, social and psychological functionality of the illness. High scores on the subscale show that the disease has negative consequences.

**Personal control:** Asks patients' perception of inner control over duration, course and treatment of the illness. High scores on the subscale indicate positive beliefs about controllability of the illness.

**Treatment control:** The patients are asked about beliefs in effectiveness of the applied treatment. High scores on the subscale indicate positive beliefs about ability to control the illness.

**Illness coherence:** Questions on the extent at which patients are able to understand or comprehend the illness are asked. High scores on the subscale indicate that the situation can be understood personally.

**Timeline (cyclical):** Questions on the various reflections of the illness throughout the timeline are asked. High scores indicate cyclical nature of the illness.

**Emotional representations:** The patients are asked about their feelings regarding the illness. High scores on the subscale indicate that emotional effects provoked by the disease and negative feelings are increased.<sup>19</sup>

**Causes of illness:** Consists of 18 items about probable reasons influential on developing of diseases. It uses 5-item Likert type (from "strongly disagree" to "strongly agree"). This part includes patients' views about potential causes of the illness and four subscales. These are psychological references, risk factors, immunity and accident or chance. In reliability and the validity study of Turkish adaptation of the questionnaire, alpha coefficients of subscale about views on illness ranged between 0.69 and 0.77, and those of the subscale about causes of illness ranged between 0.25 and 0.72. For the validity of the identity section t-test was used, the result was significant ( $t=10.49$ ,  $p<0.001$ ). Illness perception section was found to have 7 factors whereas the causes section had 4 factors and item loads (0.31-0.68 and 0.30-0.60) were satisfactory.<sup>27</sup> The alpha coefficients of the subscale about patients' views on the illness range in the present study from 0.47 to 0.77, whereas the latter ranges from 0.42 to 0.62.

#### Brief Disability Questionnaires (BDQ)

A scale comprised of nine questions investigating both bodily and social disability simultaneously was developed by the World Health Organization. Total score interval of the scale is between 0 and 22. Those with a score of 0-4 points on the scale are assessed as "having no disability", 5-7 as "having mild disability", 8-12 as "having moderate disability" whereas 13 and above as "having severe disability". Stewart et al. showed the validity and applicability of the BDQ.<sup>28</sup> The reliability and validity studies for the Turkish version of the scale in Turkey was carried out by Kaplan ( $r: 0.91$ - $p<0.001$ ) whereas the Cronbach's alpha for the total score was 0.92.<sup>29</sup> 5 points and above on the BDQ are regarded as "hav-

ing physical social disability". The Cronbach's alpha value of the present study was 0.91.

## DATA ANALYSES

Statistical analyses of collected data were carried out using Statistical Package for the Social Sciences 15. Descriptive statistics was used to analyze demographic characteristics, described the symptoms IPQ.

Patients characteristics and IPQ-BDQ values were compared using Student t test (gender), Mann-Whitney U test (marital status, social insurance) and Kruskal Wallis Variance (education, knowledge illness) analysis.

In determining the relationships between illness perceptions and disability, Pearson correlation was calculated.

## RESULTS

According to the results of the study, it was found that 53.5% of the patients were female, 77.9% were married. As for other demographic data, 73.2% of the patients were primary education or were illiterate, 86.0% were covered under social insurance. It was identified that ESRD was caused by hypertension for 36.0% of the patients whereas 61.6% had a health care assistant and 53.5% do had no

knowledge about the illness. The mean age of the patients is 53.44 years, (SD±1.49) ESRD duration 60.63 months (SD±52.34), and HD duration is 46.22 months (SD±44.63).

## ILLNESS PERCEPTION

Illness identity dimension of illness perception was provided in Table 1. The subscales about the views of patients regarding the illness provide the following mean scores in Table 2. The patient characteristics that affect the illness perception in Table 3.

## DISABILITY

The patient characteristics that affect the disability in Table 4.

## THE RELATIONSHIP BETWEEN ILLNESS PERCEPTION AND DISABILITY

The correlation analysis carried out on the relationship between HD patients' BDQ total scores and views on the illness perception in Table 5.

## DISCUSSION

This study was investigated the relationship between perception of illness and disability among patients receiving HD treatment and it has been determined during the study that the socio-demographic data of

**TABLE 1:** Illness identity dimension of IPQ.

Symptoms	I have experienced this symptom since my illness		This symptom is related to my illness	
	n	%	n	%
Pain	61	70.9	49	57.0
Sore Throat	37	43.0	21	24.4
Nausea	63	73.3	53	61.6
Breathlessness	43	50.0	28	32.6
Weight Loss	56	65.1	51	59.3
Fatigue	<b>74</b>	86.0	<b>67</b>	77.9
Stiff Joints	57	66.3	40	46.5
Sore Eyes	55	64.0	33	38.4
Wheeziness	38	44.2	25	29.1
Headaches	69	80.2	50	58.1
Upset Stomach	56	65.1	35	40.7
Sleep Difficulties	57	66.3	45	52.3
Dizziness	57	66.3	54	62.8
Loss of Strength	<b>73</b>	84.0	<b>69</b>	80.2

IPQ: Illness perception questionnaire.

**TABLE 2:** Score on the IPQ-R subscales of the subjects.

Views about illness	Mean scores $\pm$ SD	Min-max values
Personal control	18.33 $\pm$ 4.10	9-25
Timeline (acute/chronic)	21.11 $\pm$ 4.38	6-30
Timeline (cyclical)	13.37 $\pm$ 2.53	8-20
Consequences	21.12 $\pm$ 3.51	8-30
Treatment control	14.54 $\pm$ 3.29	6-20
Illness coherence	14.69 $\pm$ 14.50	5-25
Emotional representations	21.02 $\pm$ 3.43	10-28
Possible causes		
Psychological references	15.18 $\pm$ 4.20	6-24
Risk factors	19.10 $\pm$ 3.47	8-27
Immunity	5.37 $\pm$ 1.59	2-9
Accident or chance	5.11 $\pm$ 1.42	2-9

SD: Standard deviation.

patients along with their illness characteristics are in accordance with those in literature.<sup>3,7,10</sup>

It was determined in the present study that patients experienced fatigue and loss of strength most often since the onset and thus they associated mostly these two findings with their illness. Sore throat and wheeziness were the least associated findings. Likewise, other study found that HD patients that fatigue (78.8%), loss of strength (77.5%) and dizziness (62.9%) were the most commonly experienced symptoms out of 14 on the scale.<sup>30</sup> In a study, the patients experienced loss of strength and fatigue mostly since the onset of the disease and they were associated with the illness itself. On the other hand, they associated wheeziness and sore eyes with the illness at the least extent.<sup>31</sup> Other studies also show that fatigue and loss of strength are the most common symptom among HD patients.<sup>32,33</sup> All of these reports support our current results.

**TABLE 3:** The patient characteristics that affect the illness perception.

Illness Perceptions Domains	Gender <sup>a</sup>	Marital status <sup>b</sup>	Age group <sup>c</sup>	Education <sup>c</sup>	Knowledge illness <sup>c</sup>	Social insurance <sup>b</sup>
	t p	t p	t p	t p	t p	t p
Illness identity	0.756 0.452	587.0 0.605	4.354 0.113	1.670 0.644	0.255 0.880	352.0 0.249
<b>Views about illness</b>						
Personal control	0.550 0.584	577.50 0.537	10.647 0.005	5.294 0.151	3.558 0.169	327.50 0.145
Timeline (acute/chronic)	-0.656 0.514	560.50 0.426	1.849 0.397	4.004 0.261	3.023 0.221	422.0 0.783
Timeline (cyclical)	1.626 0.108	519.50 0.216	0.265 0.876	0.759 0.859	1.831 0.400	371.50 0.359
Consequences	0.497 0.620	541.0 0.316	2.102 0.350	1.495 0.683	0.726 0.696	401.0 0.589
Treatment control	-0.993 0.324	551.0 0.370	1.624 0.444	5.691 0.128	2.120 0.346	428.50 0.846
Illness coherence	-0.362 0.718	604.0 0.733	10.218 0.006	5.906 0.116	9.390 0.009	374.50 0.382
Emotional representations	2.522 0.014	510.50 0.184	6.342 0.042	4.813 0.186	5.242 0.073	439.0 0.950
<b>Possible causes</b>						
Psychological references	2.120 0.037	558.50 0.414	6.450 0.040	15.550 0.001	11.596 0.003	326.0 0.139
Risk factors	0.197 0.844	440.00 0.040	8.459 0.015	3.454 0.327	6.128 0.047	373.0 0.374
Immunity	-0.150 0.881	574.00 0.496	2.893 0.235	7.166 0.067	1.663 0.435	430.50 0.860
Accident or chance	0.40 0.690	628.50 0.929	6.714 0.035	4.654 0.199	1.802 0.406	418.0 0.729

<sup>a</sup>: t test; <sup>b</sup>: Mann Whitney U test; <sup>c</sup>: Kruskal Wallis test.

**TABLE 4:** The patients characteristics that affect the disability.

Patients characteristics	n	BDQ	
			(M ± SD)
<b>Gender</b>			
Female	46		13.87 ± 5.81
Males	40		12.42 ± 4.98
t			1.228
P			0.223
<b>Marital status</b>			
Married	67		13.60 ± 4.75
Single	19		11.79 ± 7.43
U			571.50
p			0.498
<b>Age</b>			
<50	34		9.82 ± 5.30
50-60	24		14.87 ± 3.97
60<	28		15.86 ± 4.68
Kruskal Wallis			22.721
P			<0.001
<b>Educational level</b>			
Illiterate	26		17.15 ± 3.26
Primary and Secondary	37		11.46 ± 4.65
Tertiary	10		12.50 ± 6.38
High School	13		10.77 ± 6.61
Kruskal Wallis			24.134
P			<0.001
<b>Knowledge of illness</b>			
Yes	22		11.04 ± 5.89
No	46		14.39 ± 4.68
Partially	18		12.78 ± 6.19
Kruskal Wallis			4.564
P			0.102
<b>Social insurance</b>			
Yes	74		12.88 ± 5.42
No	74		15.17 ± 5.52
U	12		315.50
P			0.108

M: Mean; SD: Standard deviation; BDQ: Brief disability questionnaire.

According to the subscales regarding patients' views on the illness; mean scores obtained from timeline (acute/chronic), emotional representations

and perception of consequences were found to be higher in comparison with others. The lowest mean score was calculated for perception of timeline (cyclical). High scores of subscales investigating patients' perceptions of timeline of their illness (acute/chronic) indicate that the views of most patients, considering wordings in timeline perception that the illness will last for a long period of time, that it is a permanent disease rather than temporary and they that have to bear with it for the rest of their life, that it won't get better in the course of time. According to the results, patients believe that their illness is a chronic disease; they accept this fact and bear few hopes of recovery. Higher mean scores on emotional representations and perception of consequences in comparison with other dimensions indicate that patients experience negative feelings intensely that are due to or evoked by the illness; the illness has serious consequences and affects their life seriously.

In addition, Timmers et al. reported a higher perception of timeline (acute/chronic) and consequences in comparison with other subscales in HD patients.<sup>2</sup> Kim and Evangelista use the same scale in their study and identified higher mean scores on emotional representations such as perception of timeline (acute/chronic), consequences, personal and treatment control whereas other study found higher scores on emotional representations and perception of consequences in comparison with those of the other subscales. These findings seem to support those of our study.<sup>30,31</sup>

Considering the wordings in the subscale; low scores on perception of timeline (cyclical) indicate that patients' symptoms do not vary or that they do not go through good or bad times; that patients think the disease can be predicted. Moreover, low mean scores on perception of timeline (cyclical) re-

**TABLE 5:** Correlations between illness perceptions and disability.

	Personal control	Timeline (acute/chronic)	Timeline (cyclical)	Consequences	Treatment control	Illness coherence	Emotional representations	Psychological references	Risk factors	Immunity	Accident or chance
BDQ	r=0.288, p=0.007	r=0.145, p=0.184	r=0.072, p=0.509	r=0.425, p<0.001	r=-0.118, p=0.385	r=-0.210, p=0.022	r=0.312, p=0.003	r=0.297, p=0.006	r=0.198, p=0.068	r=0.161, p=0.139	r=0.117, p=0.285

BDQ: Brief disability questionnaire.

ported by other studies show that HD patients bear similar perceptions in this regard.<sup>2,30,31</sup>

Negative perceptions of the illness lead to intensive experience of psychological challenges like unhappiness and depression as well as increased mortality.<sup>21,22</sup> On the contrary, it was detected that positive perception of illness in ESRD patients also affects self-esteem and autonomy in a positive way.<sup>23</sup> Patients experienced fatigue and loss of strength associated with their illness in this study as well and they reported negative perceptions of illness on dimensions such as timeline, consequences and emotional representations. This result can be explained with the fact that participants suffer from ESRD as a disease that is difficult to cure and manage and receive HD treatment.

When scale items are considered, it is observed that the scores of HD patients regarding possible causes of the illness reveal that the respondents designate genetic facts, senility, bad habits, stress, family-related problems and personal traits as the most common causes of their illness. The lowest scores were calculated for chance and accident factors. Patients are of the opinion that they suffer CKF because of chronic diseases with high genetic transmission, diabetes and hypertension that cannot be managed well along with psychological agents like stress during development of the illness. Other study has compliant findings that patients appoint risk factors and psychological references most as causes of their illness.<sup>31</sup>

The relationship between perception of illness and some variables reveals that female participants obtained higher mean scores on emotional representations and psychological references. Female patients experience negative feelings caused by the illness more deeply than males, and associate their illness mostly with psychological attributes. In addition, Kim and Evangelista found that females perceive more symptoms than males and they similarly reported higher scores on emotional representations.<sup>30</sup> The fact that women are more sentimental-intuitional in both biological and social aspects than men can account for these findings.

When mean scores of marital status and illness identity, views on the illness and possible causes

was compared with the mean scores for only the risk factors involved; it was determined to be greater in married subjects. Younger patients reported higher perceptions of personal control, illness coherence and emotional representation.

In this study, patients who had low knowledge scores about the illness reported illness-related negative feelings more intensely. But the other participants with better illness coherence were able to associate with risk factors and psychological references. Lack of knowledge is one of the most important diagnoses in nursing. Lack of informing by nurses and other health professionals about the illness might lead to the development of negative attitudes and beliefs about their illness in patients.

In this study, distribution of BDQ scores of HD patients shows that 22.1% reported moderate disability and 60.5% developed severe disability. The difference between education level, age and BDQ mean scores was significant; the mean scores of illiterate and older participants were highest while high school graduates and the younger patients received the lowest mean scores.

While HD impairs metabolic status, it also causes disabilities thereby restricting daily life activities of patients and having negative effects on self-care competence due to the nature of both ESRD and dialysis process applied in the treatment<sup>7</sup>. In accordance with literature, more than half of the patients in our study experienced disability at moderate to severe extents. According Erdenen et al., the total score of disability was found to be significantly higher in comparison with that of the normal population. Accordingly, 26.67% of the HD group showed mild disability whereas 40% showed moderate and 14.67% showed severe disability.<sup>10</sup> Furthermore, Mol-laoğlu found that 36.8% of the HD patients developed moderate level disability, while 6.6% developed severe disability.<sup>7</sup>

Regarding the relationship between disability and other variables, those who are illiterate and older patients were found to have more severe disability in comparison with others. Also in other study, HD patients without any education background reported disability at moderate to severe

levels.<sup>10</sup> These findings support our study results. It might be because patients have disability whose disease could affect whole body.

Regarding the relationship between BDQ scores and subscales of views on the illness and possible causes obtained by HD patients, the participants with high levels of disability also have high perceptions of consequences, timeline (acute/chronic), emotional representations and psychological references. So, patients who perceive their illness as chronic, its unwanted consequences, negative feelings evoked by the illness and explain the illness with psychological problems like stress, anxiety, family problems, and personality traits experience high levels of disability.

There is a significant negative correlation between BDQ and subscales of illness coherence and personal control. Results of the study indicate that patients without illness coherence and low perception of illness control face high levels of disability.

In addition to these results, participants of the study who experience high levels of disability were found to have a high illness identity. Those experiencing higher levels of disability perceive more symptoms of the illness.

No significant relationship was found between BDQ and mean scores on subscales of treatment control, risk factors, immunity, timeline (cyclical) and accident or chance. In a study carried out, on illness perception and quality of life HD and peritoneal dialysis patients; it has been determined that perception of personal control is related with physical and social functions, body aches and general health perception.<sup>2</sup> Other studies addressing illness perception and quality of life in HD patients also reported similar findings.<sup>34-36</sup> Chilcot et al. carried out, a correlation between low personal control and illness coherence as well as negative perception of consequences and depression in HD.<sup>37</sup> Another study carried out, on illness perception and mortality; it has been put forth that perception of treatment control could be a sign of mortality independent on comorbidity and risk factors.<sup>38</sup> According to the study carried out a relationship was detected between negative illness perception and adherence to diet whereas O'Connor et al. identified a relation between emotional percep-

tions and diet as well as emotional and timeline perceptions and adherence to medication.<sup>33,39</sup>

Problem solving skills such as managing the illness, coping with emotional status and symptoms caused by HD can be acquired in HD patients and accompanying problems may be overcome if perception of illness is assessed and the perceptions of the patients regarding their illness are affected in a positive way.

The present study also puts forth a relationship between the negative perceptions of patients' regarding their illness and disability. Thus, disability can be reduced in HD patients who necessarily experience fatigue and loss of strength and high levels of disability if nursing interventions are made to affect their perceptions positively. As a result, their quality of life can be increased and cost effective results can be reached.

## CONCLUSION

It was determined that patients with high levels of disability also show high perceptions of consequences, timeline (acute/chronic), emotional representations, and psychological references, they cannot provide illness coherence and control the illness, also have high perceptions of illness identity. Furthermore, no significant relationship was found between scores calculated from BDQ and subscales of treatment control, risk factors, immunity, timeline (cyclical) and accident or chance.

The present study is the first example that investigates the correlation between perception of illness and disability in HD patients in Turkey. Thus, it is likely to guide the development of nursing services in order to improve quality of life patients not only in HD units but also in the overall community. We recommend that similar studies are performed on larger sample groups and that they are designed as experimental studies so that the relationship between perception of illness and disability can be highlighted better in HD patients.

The study data were obtained with a relatively small sample size only in two hospitals in Turkey. Therefore, the results may not represent all patients with HD.

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