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The Effect of the Symptom Level on the Illness Perception in Individuals Undergoing Hemodialysis: Cross-Sectional Study

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ABSTRACT:
Purpose: This research was conducted to identify the effect of the symptom level on the illness perception in individuals undergoing hemodialysis.
Material and Methods: The study was performed with 240 participants who had the hemodialysis procedure in dialysis units of hospitals and one private dialysis center in a province and satisfied the criteria to be included in the research.
Results: In the study, it was found that nearly all patients experienced symptoms such as itching, numbness/tingling in the feet, feeling tired and dry skin. In the sample group that had a negative illness perception, it was found that the symptoms experienced alongside the hemodialysis procedure affected the illness perception, and there was a moderately positive relationship between these two variables.
Conclusions: In this context, it was recommended that the frequency and the severity of symptoms of patients undergoing hemodialysis should be regularly followed and these patients' illness perception levels should be evaluated.
Keywords: *Illness perception; hemodialysis; symptom*

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INTRODUCTION

The end-stage renal disease, which is a crucial public health issue in Turkey and across the world, is a chronic condition resulting in the loss of kidney functions, leading to the uremic syndrome, and requiring a complex treatment procedure (Akyol, 2016; Chaiviboontham et al., 2020). In Turkey, the point prevalence of end-stage renal disease requiring renal replacement was identified as 993.5 in one million as of the end of 2021 (Ministry of Health and Turkish Society of Nephrology Joint Report, 2019). The hemodialysis procedure is one of the most preferred treatment methods for raising the quality of life and lowering mortality and morbidity rates in patients diagnosed with end-stage renal disease, however, it gives rise to numerous symptoms affecting the quality of life of patients (Dikmen and Arslan, 2020; Taşkın Yilmaz et al., 2020). Fatigue, itching, muscle cramps, nausea-vomiting, lack of appetite, edema, sleep problems, the feeling of uneasiness, and sexual dysfunction are among the most frequently exhibited symptoms (Dikmen and Arslan, 2020; Hindistan and Deniz, 2018; Taşkın Yilmaz et al., 2020). These symptoms exhibited during the hemodialysis procedure make the process difficult for patients as fully relaxing therapies have not been found yet. Failing to define patients' symptoms adequately most of the time is underlined as the most significant factor leading to this situation. Also, it is stated that, to a large extent, health workers are uninformed about the physical and emotional symptoms of patients constantly

undergoing hemodialysis and are unaware of the seriousness of these symptoms (Cho et al., 2018). In studies of KDIGO (Kidney Disease Improving Global Outcomes) on complementary care for the illness, it is advocated that patients undergoing hemodialysis should be routinely screened in terms of symptoms, and it is necessary to identify the affected areas of life (National Kidney Foundation, 2013; Cox et al., 2017). Patients undergoing hemodialysis have difficulty in continuing their daily life activities, as well as entertainment and social activities, depending on the symptoms experienced by them. The resulting situation disrupts the physical and psychological well-being of individuals and affects their quality of life and illness perception levels (Akgöz and Arslan, 2017; Nabolsi et al., 2015).

Illness perception is a concept directly affecting individuals' experiences during the illness period, illness process, and coping mechanisms and is an implication of their beliefs and expectations about any illness or symptom (Karabulutlu and Karaman, 2015; Karatay and Sevinç, 2016). How an illness is perceived by an individual plays a significant role in the individual's coping with illness symptoms and their consequences as well as affecting the individual's life in all dimensions (Jonsbu et al., 2012; Steca et al., 2013). The illness process is shaped by the patient's perception of the illness and illness-related experiences, and hence, the meaning of experienced symptoms differs for each patient (Karabulutlu and Karaman, 2015; Uysal and Akpınar, 2013). As well as the medical symptoms, findings, and diagnosis of a physical illness, the way in which a person perceives the illness affects the consequences of the illness. Thus, finding out how an illness is perceived, as well as identifying the factors affecting the illness perception, is important to understanding the experienced problems and planning the relevant interventions (Karabulutlu and Karaman, 2015). It is reported that the negative illness perception leads to intense unhappiness and depression and increases mortality whereas it is accepted that the positive illness perception supports self-esteem and autonomy. In light of the above points, it is important to evaluate illness perceptions of hemodialysis patients who are risky in terms of the change in the illness perception due to the illness process and the symptom load. In the relevant literature, it is possible to find studies that analyzed the symptoms in individuals undergoing hemodialysis and examined the relationship between these symptoms and variables such as depression, anxiety, dependence, and quality of life (Akgöz and Arslan, 2017; Bai et al., 2015; Dikmen and Arslan, 2020; Nabolsi et al., 2015). However, it is discerned that the relationship between illness symptoms and illness perception was not adequately examined, and there were a limited number of studies in the relevant literature in Turkey and across the world. In fact, illness perception is quite important to perceiving the symptoms, making sense of them, and planning interventions to eliminate them. In this context, it is considered that this study will fill the above gap in the relevant literature and present scientific data for the improvement of nursing practices that are used in hemodialysis units.

MATERIAL and METHODS

Purpose and Type of the Study

The research aims, to find out the illness perception and symptom levels of individuals undergoing hemodialysis, to identify the relationship between these two variables, and, to reveal socio-demographic and illness-related factors affecting the symptom level and illness perception.

Sampling and participant

The research population is a total of 280 individuals undergoing hemodialysis in dialysis units of a university hospital and a public hospital and a private dialysis center. The sample size for the research was not calculated, rather, efforts were made to contact all individuals satisfying the criteria to be included in the research sample, and hence, the study was concluded with a total of 240 participants. In the research, the inclusion criteria were designated as (1) being diagnosed with chronic renal disease and accordingly continuing to undergo hemodialysis for a minimum of one year, (2) being aged 18 years or above, (3) having no cognitive disorder and communication barrier, and (4) agreeing to participate in the study upon being informed about the research. Individuals whose dialysis treatment

duration was more than one year and who were under the age of 18 were not included in the sample.

Data Collection Tools

Researchers collected the research data by visiting dialysis centers from 1 January 2023 to 1 May 2023. Participant patients who were divided into two groups were undergoing hemodialysis in three times every week (the first group on Monday, Wednesday, and Friday, and the second group on Tuesday, Thursday, and Saturday), and researchers visited dialysis centers every day except Sunday. The research data were collected with the face-to-face interview technique in the period when the patient underwent hemodialysis and felt comfortable. After patients consented to join the research upon being informed about it, surveys were administered to patients in a convenient meeting room in dialysis centers. On average, it took 15-20 minutes to administer the surveys to a patient. The research data were collected with the survey forms detailed below.

Descriptive Information Form

Prepared by researchers in light of the relevant literatüre (Dikmen and Arslan, 2020; Hindistan and Deniz, 2018), this form contained 14 questions seeking to find out patients' sociodemographic characteristics and illness- and treatment-related data.

Dialysis Symptom Index (DSI)

Weisbord et al. (2004) developed the DSI to identify the hemodialysis patient's symptoms and how much these symptoms affected the patient. Developed from the Memorial Symptom Assessment Scale Short Form, the DSI comprises 30 items. Whether a symptom has been experienced for the last seven days is answered by the respondent as either yes or no. If the respondent's answer is yes, how much the symptom has affected the respondent is evaluated through a five-point Likert scale (1= Never, 2= Little, 3= Somewhat, 4= Much, 5= A Great Deal). A respondent's total DSI score is calculated by summing all points obtained from each DSI item. The total DSI score ranges from 0 to 150 points. A total DSI score of 0 shows that the respondent exhibits no symptoms. A total DSI score approaching 150 points indicates that symptoms have a large effect on the respondent. Önsöz and Usta Yeşilbakan (2013) performed a validity and reliability study for the DSI in Turkish. In the study by Önsöz and Usta Yeşilbakan (2013), Cronbach's alpha coefficient was calculated as 0.73 for the DSI.

Brief Illness Perception Questionnaire (B-IPQ)

The B-IPQ developed by Broadbent et al. (2006) has eight sub-scales containing open-ended response items and rated from 0 to 10 points. The first sub-scale is "Consequences" (How much does the illness affect your life?), the second sub-scale is "timeline" (How long do you think your illness will continue?), the third sub-scale is "personal control" (How much control do you have over your illness), the fourth sub-scale is "Treatment control" (How much do you think your treatment will help your illness?), the fifth sub-scale is "Identity" (to what degree do you experience symptoms related to your illness?), the sixth sub-scale is "concern" (how much are you concerned with your illness?), the seventh sub-scale is "understanding" (how well do you understand what your illness is?), and the eighth sub-scale is "emotional representation" (how much does your illness affect you emotionally?). High scores obtained from the B-IPQ and its sub-scales refer to negative illness perceptions (Kahyaoğlu Süt, 2017). In our study, Cronbach's alpha coefficient was calculated as 0.80 for the B-IPQ.

Statistical Analysis

The data were analyzed by using the SPSS 22.0 software (SPSS, Inc., Chicago, IL, USA). In the statistical analysis of the study, the mean value was taken, the Kolmogorov-Smirnov Z test was used to test the normal distribution of the scale means, Independent Sample T test, One Way Anova and the Kruskal-Wallis test was applied. To determine the relationship between itching and sleep quality, Pearson's correlation analysis was utilized. The statistically significant level was accepted as $p<0.05$.

Ethical Approval

Before the research, the written ethical endorsement was obtained from the ethics

committee of a university (Decision no: 2022-10/16), and also, permissions were received from institutions where the research would be carried out. Besides, each patient to be included in the research was informed about the research content and was told that participation in the research was voluntary, and then, the patient submitted an informed consent form. The study was conducted in full compliance with the principles of the Declaration of Helsinki.

RESULTS

Participants' sociodemographic and clinical characteristics

It was found that the mean age of the sample group was 61.78±1.41 years, and of all participants, 52.1% were male, 63.3% were primary school graduates, 74.6% were married, 58.3% were undergoing hemodialysis for 1-5 years, and nearly all of them (90.8%) had an illness history other than chronic renal disease.

Symptoms experienced by participants

In Table 1, the symptoms of participant patients undergoing hemodialysis and the severity of their symptoms were exhibited in the context of the DSI. In Table 1, symptoms affecting patients most frequently are listed as itching (%99.2), numbness or tingling in the feet (%98.8), feeling tired/decreasing energy (%98.8), dry skin (%98.3), difficulty in falling asleep (%97.9) and staying asleep (%97.1), lack of appetite (%97.1), muscle cramps (%95.8), and feeling sick (%95.8), and it is discerned that these symptoms were experienced by nearly all participant patients.

Participants' mean DSI and B-IPQ scores

Table 2 indicated the mean DSI score of participant patients, as well as mean scores obtained by patients from the B-IPQ and its sub-scales.

Table 1. Symptoms experienced by participants (n:240)

Symptoms	Symptom frequency	Symptom severity (min:0 max:5)
	n (%)	Mean ±sd
Itching	238 (99.2)	3.21±0.96
Numbness or tingling in feet	237 (98.8)	3.12±1.02
Feeling tired or lack of energy	237 (98.8)	3.51±0.89
Dry skin	236 (98.3)	3.55±0.97
Difficulty falling asleep	235 (97.9)	3.52±1.00
Decreased appetite	233 (97.1)	3.08±1.09
Difficulty staying asleep	233 (97.1)	3.70±2.79
Muscle cramps	230 (95.8)	1.22±0.77
Feeling sick	230 (95.8)	3.44±1.10
Drowsiness/dizziness	212 (88.3)	1.47±0.96
Dry mouth	212 (88.3)	2.44±1.23
Difficulty keeping legs still	211 (87.9)	2.18±1.36
Feeling anxious	201 (83.8)	2.18±1.48
Feeling sad	190 (79.2)	1.58±1.27
Muscle pain	189 (78.8)	1.93±1.32
To worry	188 (78.3)	1.45±1.17
Constipation	181 (75.4)	1.42±1.12
Headache	180 (75.0)	1.10±0.93
Nausea	173 (72.1)	0.91±0.79
Bone and joint pain	163 (67.9)	1.70±1.48
Difficulty concentrating	157 (65.4)	1.06±1.03
Cough	137 (57.1)	0.95±1.17
Shortness of breath	134 (55.8)	3.09±1.87
Feeling angry	124 (51.7)	0.81±1.11
Vomiting	117 (48.8)	0.51±0.72
Diarrhea	111 (46.2)	0.62±0.86
Decreased interest in sex	104 (43.3)	1.35±1.76
Difficulty getting sexual satisfaction	103 (42.9)	1.30±1.76
Swelling in the legs	96 (39.8)	3.77±1.68
Chest pain	85 (35.4)	0.41±0.84

Table 2. Participants' mean DSI and B-IPQ scores

SCALES	Score range	Min-Max	Mean±sd
DSİ Total	0-150	0-96	57.05±14.27
B-IPQ Total	0-80	17-75	62.78±7.86
1. Consequences	0-10	1-10	8.15±1.41
2. Timeline	0-10	2-10	9.16±1.75
3. Personal control	0-10	1-10	7.06±1.52
4. Treatment control	0-10	2-10	9.29±1.37
5. Identity	0-10	2-10	7.70±1.23
6. Concern	0-10	1-10	7.17±1.67
7. Understanding	0-10	1-10	7.93±1.50
8. Emotional representation	0-10	1-10	6.29±1.77

Table 3. The relationship between participants' DSI and B-IPQ scores

DSI	B-IPQ	Consequences	Timeline	Personal control	Treatment control	Identity	Concern	Understanding	Emotional representation
r	0.326	0.357	0.146	0.046	0.154	0.350	0.333	0.059	0.366
p	0.000	0.000	0.024	0.474	0.017	0.000	0.000	0.364	0.000

Table 4. The comparison of participants' mean DSI and B-IPQ scores as per certain socio-demographic variables

Variables	DSI Mean±sd	B-IPQ Mean±sd
Gender		
Women	59.71±15.16	62.81±9.45
Men	55.04±13.49	62.75±6.08
t/p	2.521/**0.012**	0.064/0.950
Age		
18-39 year	56.12±16.63	63.66±8.57
40-50 year	58.80±13.71	63.58±7.04
> 50 year	56.80±14.00	61.87±8.01
F/p	0.635/0.531	1.469/0.232
Education level		
Literate and lower	60.62±16.82	63.50±6.46
Primary school	56.20±13.68	62.02±8.76
High school and higher	55.20±11.45	65.66±3.27
KW/p	4.665/**0.010**	4.392/1.111
Marital status		
Single	54.04±15.19	63.06±7.30
Married	58.38±14.10	62.68±8.06
t/p	1.073/**0.043**	0.324/0.734
Duration of disease		
1-5 years	56.05±15.29	62.42±7.82
6-10 years	58.23±12.90	62.35±8.75
> 10 years	59.90±13.62	64.67±6.38
F/p	0.837/0.434	1.395/0.250
Other disease		
Yes	57.15±14.64	65.57±8.12
No	56.04±10.05	64.86±4.05
MU/p	2.240/0.609	2.073/0.294

According to these mean scores, it was found that patients had a nearly medium level of symptom severity and nearly negative illness perception. Upon the review of patients' mean B-IPQ sub-scale scores, it was identified that patients obtained relatively high mean scores from B-IPQ sub-scales of "consequences", "timeline", and "treatment control".

The relationship between participants' DSI and B-IPQ scores

In Table 3, which analyzed the relationship between participant patients' DSI and B-IPQ scores, it was discerned that patients' DSI scores had moderately positive relationships with their B-IPQ scores and B-IPQ "consequences", "identity", "concern", and "emotional representation" sub-scale scores and weak positive relationships with their B-IPQ "timeline" and "belief in the treatment" sub-scale scores.

The comparison of participants' mean DSI and B-IPQ scores as per certain socio-demographic variables

In the analysis for the comparison of participant patients' mean DSI and B-IPQ scores as per certain socio-demographic variables, it was found that patients who were female, patients who were illiterate, and patients who were married obtained higher mean DSI scores than other corresponding groups of patients and these differences between groups of patients were statistically significant whereas other socio-demographic variables had no statistically significant effect on hemodialysis symptom levels. In the study, also, patients' illness perceptions were examined as per certain socio-demographic variables, however, it was discerned that there was no statistically significant difference between groups of patients in terms of illness perception (Table 4).

DISCUSSION

In this study that was performed to identify the relationship between symptoms and the illness perception in patients undergoing hemodialysis, it was discerned that the most common physical symptoms were itching, numbness/tingling in the feet, dry skin, lack of appetite, and sleep problems whilst feeling anxious, upset, and angry and worrying were the most common psychological symptoms. In the study by Akgöz and Arslan (2017), feeling tired and a decrease in energy (74.3%), headache (62.9%), and bone and joint pains (61.0%) were identified as symptoms experienced most by the patients. Findings in support of the result of our study were obtained also in studies conducted with similar groups of patients in Turkey (Göriş et al., 2016; Taşkın et al., 2020). In the study by Almutary et al. (2013), it was stated that symptoms such as fatigue or lack of energy, feeling sleepy, pain, itching, and dry skin were experienced most frequently by patients undergoing hemodialysis, and also, it was asserted that psychological symptoms such as feeling anxious, worrying, nervousness, and sadness were disturbing for patients. In the study by Zamanian and Kharameh (2015), it is discerned that the most reported physical symptom was fatigue (85.3%) while the most reported psychological symptom was uneasiness (77.9%). The study by Chaiviboontham et al. (2020) listed the most experienced symptoms as itching, dry skin, muscle pain, dry mouth, muscle cramps, and difficulty in staying asleep. In a similar vein, the study by Cho et al. (2018) stated that constipation, dry skin, itching, fatigue, muscle cramps, sleep problems, and anxiety were frequently experienced by patients. It is discerned that the result on the rates of symptoms in our research was consistent with the relevant literature. Numerous symptoms experienced during the hemodialysis treatment affect individuals' daily life activities and makes the process of adaptation to the illness difficult by leading to role changes, disruption in family life, and changes in body image and self-esteem. Therefore, it is important to identify these symptoms and plan interventions aimed at controlling them.

Moreover, in the current study, itching was identified as one of the symptoms that had the highest severity and were exhibited most by patients. Itching is a disturbing symptom experienced by patients diagnosed with chronic renal disease. Factors, such as the accumulation of waste materials on the skin due to the inability to get rid of them from the body and the loss of skin moisture along with aging, are known to have significant effects on symptoms of dry skin and itching (Dikmen and Arslan, 2020). Even if itching alone is not a life-threatening problem, it affects the quality of life and daily life activities of patients, leads to anxiety, depression, and physical and mental fatigue, and shapes the patient's adaptation to the illness in a negative direction (Pereira and Stander, 2017; Simonsen et al., 2017).

In previous studies, it is discerned that another highly severe symptom experienced frequently by patients undergoing hemodialysis was fatigue. The L-carnitine deficiency due to the increase in bodily excretions and decrease in kidney performance during the dialysis treatment process leads to fatigue in patients undergoing hemodialysis. Besides, anemia, sleep disorders, malnutrition, and changes in mental status increase fatigue levels (Hindistan and Deniz, 2018; Cox et al., 2017). Also in different studies in the relevant literature, fatigue and decrease in energy are reported as frequently experienced symptoms (Bossola et al., 2018; Dikmen and Arslan, 2020; Hindistan and Deniz, 2018). It is put forward that the symptoms experienced frequently by hemodialysis patients, such as numbness in the feet and bone/joint pain, were often associated with the rise in the potassium level, uremia, and iron-deficiency anemia. Likewise, it is stated that symptoms related to the gastrointestinal system, such as constipation, nausea, vomiting, and the lack of appetite, were associated with abnormal BUN (blood urea nitrogen) levels, inadequate dialysis, and drug side effects (Chaiviboontham et al., 2020). It is emphasized that controlling these symptoms was an integral part of illness management. It is suggested that individuals' adaptation to the illness and their coping with the illness developed and their perceptions of the illness improved through the nurses' understanding of the symptoms and planning of the most suitable nursing intervention plans related to symptoms (Cho et al., 2018).

Furthermore, in the current study, patients' mean DSI and B-IPQ scores were compared as per certain variables. In the analysis, it was found that patients who were female, patients who were married, and patients who were illiterate obtained significantly higher mean DSI scores than other corresponding groups of patients whereas other variables had no statistically significant effect on hemodialysis symptom levels. Likewise, in the study by Hindistan and Deniz (2018), it was found that participants who were illiterate and participants who were female obtained significantly higher mean DSI scores. Similar results were found also in the study by Caplin et al. (2006) and the study by Göriş et al. (2016). In the relevant literature, there are different studies supporting the findings of our research (Kim and Evangelista, 2010; Weisbord et al., 2004). Higher symptom load and severity levels in women undergoing hemodialysis can be associated with women's higher illness perception levels and the continuation of their socially designated roles and responsibilities during the treatment process (Akgöz and Arslan, 2017). Besides, in our study, it was found that patients with relatively low-level education were more affected by hemodialysis-related symptoms. In similar studies conducted with patients undergoing hemodialysis, it was identified that patients with high education levels obtained higher mean physical health scores than those with low education levels (Göriş et al., 2016; Hindistan and Deniz, 2018). It is considered that patients will use coping mechanisms better and cope with illness symptoms more successfully as their education levels increase. The ability to control illness symptoms more easily along with the increase in an individual's self-care power as the education levels rise (Akgöz and Arslan, 2017) can be considered as the reason for obtaining this finding.

The presence of illness symptoms affects the ways of individuals to perceive the illness. The illness perception is defined as the patient's beliefs about the illness and cognitive outlook toward the illness, and this outlook is shaped by the experience of illness symptoms (Karabulut and Karaman, 2015). In the current study, the relationship between patients' DSI and B-IPQ scores was analyzed, and it was found that patients' DSI scores had moderately positive relationships with their B-IPQ scores and B-IPQ "consequences", "identity", "concern", and "emotional representation" sub-scale scores. In light of this finding, it can be said that hemodialysis patients who had a high symptom load were more affected by the illness process, felt their illness-related complaints more intensely, were more worried about their illness, and were more emotionally affected by the illness. Symptoms experienced during the illness process create a "symptom load" in hemodialysis patients. Influencing individuals' lives, the symptom load causes individuals to perceive the illness negatively and feel worried and anxious about the illness. Prompting negative physical, psychological, and

emotional reactions in general, this situation makes it difficult to cope with the illness and leads to a negative illness perception (Almutary et al., 2013). In the study by Karabulutlu and Karaman, it was found that hemodialysis patients experiencing fatigue and power loss had negative perceptions of the illness duration, illness consequences, and emotional representations.

This result was explained by the view that participants accepted chronic renal disease as an illness that is difficult to cure and manage. In the study by Schick-Makaroff and Molzahn (2017), it was identified that patients experiencing symptoms such as fatigue, sleep problem, itching, loss of appetite, and feeling unwell were more affected by the illness, and as the symptom seriousness of the illness increased, the negative illness perception increased and coping with the illness became more difficult. In studies conducted with groups of patients diagnosed with diseases other than the chronic renal disease, it was identified that there was a relationship between illness symptom seriousness and illness perception, and as the symptom load increased, the illness perception was negatively affected (Knowles et al., 2017; Kalfoss et al., 2019). Patients undergoing hemodialysis have to cope with numerous symptoms throughout the illness process (Akgöz and Arslan, 2017). Considering that these symptoms affected the illness perception negatively, it can be asserted that planning the nursing services necessary to enhance the hemodialysis patient's adaptation to the illness is important.

Study Limitations

Our study has certain limitations. As this study was carried out in three dialysis centers in our province in Turkey, its results cannot be generalized to the entire population. Through multi-center studies, it will be possible to identify general symptom clusters in the population of Turkey. Also, this study was performed in a specific period, and as symptoms can change over time, studies that continuously conduct follow-ups are needed.

CONCLUSION

In the study, it was found that nearly all patients experienced symptoms such as itching, numbness/tingling in the feet, feeling tired/decreasing energy, dry skin, difficulty in falling asleep and staying asleep, lack of appetite, and muscle cramps. In the sample group that had a negative illness perception, it was found that the symptoms experienced alongside the hemodialysis procedure affected the illness perception, and there was a moderately positive relationship between the two variables. In this context, it can be recommended that the frequency and severity of symptoms of patients undergoing hemodialysis be regularly followed and these patients' illness perception levels be evaluated. Also, it can be said that, by controlling hemodialysis symptoms effectively, the illness perception can be shaped in a more positive direction. It is considered that research results can guide the care planning and care practice and the preparation of symptom protection programs for patients.

Conflict of Interest

There are no potential conflicts of interest.

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