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Dates: Received: 12 October, 2015; Accepted: 07 November, 2016; Published: 08 November, 2016

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Keywords: Illness perception; Hopelessness; Hemodialysis patients

Research Article

Illness Perception and Hopelessness in Hemodialysis

Abstract

Background: Illness perception is useful in understanding the impact of hopelessness on ESRD patients. This perception has been found to be an important determinant of behavior and has been associated with a number of important outcomes such as treatment adherence and functional recovery and quality of life.

Aim: The aims of this study were to determine, the level of hopelessness and to evaluate whether illness perception is related to hopelessness among End-stage Renal Disease (ESRD) patients on hemodialysis (HD).

Methods: The study was conducted on patients with end stage renal disease who received treatment in the dialysis units and who volunteered to participate in the study. A total of 83 HD patients completed the Revised Illness Perception Questionnaire (IPQ-R) and Beck Hopelessness Scale (BHS) to measure the level of hopelessness.

Results: Result shows that there was significant relationship found between hopelessness and illness perception. Five components of illness perception which included consequences, personal control, treatment control, illness coherence, emotional response and causes were significantly correlated with hopelessness. HD patients believing that their illness was chronic and due to illness occurs most of stress-worry.

Conclusions: Interventions aimed at providing more knowledge about ESRD and dialysis, and provision of skills to coping with the illness and its consequences may reduce hopelessness in dialysis patients. The way the patients feels and believes regarding one self, the disease and also the treatment will usually affect his or her life. Additionally, the relationship between the five components of illness and hopelessness provide support for pursuing further examination of the holistic outcomes in persons with ESRD patients undergoing haemodialysis.

Introduction

Illness perceptions refer to organized beliefs surrounding the symptoms, consequences, time course, controllability, and causes of an illness [1]. Hemodialysis patients may be faced with serious stressors related to the illness and its treatment, arising from the chronic nature of ESRD and the intrusiveness of the medical treatment. Patients are often confronted with limitations in food and fluid intake; with physical symptoms such as itching and lack of energy; with psychological stressors such as loss of self-concept and self-esteem, feelings of uncertainty about the future, and feelings of guilt towards family members; and with problems in the social domain [2-4]. Illness perceptions have been shown to be important determinants of functional and psychosocial outcomes, including quality of life and treatment adherence in end-stage renal disease patients [1].

The concept of illness perception is useful in understanding the impact of hopelessness on ESRD patients. Hopelessness has been described in several ways [5]. It is widely understood to be the polar opposite of hope; it is the feeling that goal attainment is impossible and therefore not worth trying [6]. Hopelessness has also been described as a state where hope is completely lost. Furthermore, hopeless people are believed to not enjoy life nor be capable of making plans about the future. Hopelessness has been associated with diminished physical, psychological, mental, and spiritual health. Loss

of hope, accompanied by narrowing expectations and goals for life, is believed to reduce patients' QOL [6,7].

It is becoming ever more evident that among patients with physical illnesses, the subjective experience of well-being and perceptions of the illness experience is strongly associated with psychosocial and health-related outcomes [2,3,8]. Specifically, illness perceptions have been studied extensively; they help predict wide-ranging outcomes across several illness groups [9,10].

Less is known about the illness perceptions of dialysis patients or about the relationship between illness perceptions and hopelessness in this patient group. The aims of the present study were to investigate the illness perceptions of hemodialysis patients, and to examine the relationship between these perceptions and hopelessness.

Materials and Methods

The participants in this study included 83 patients with ESRD who were undergoing Hemodialysis treatment at outpatient in two dialysis center of Sivas, Turkey. Individuals who were alert, could communicate verbally, could understand the questions, lived in Sivas and were willing to participate in the research were included in the research sample. Of the total of 110 individuals, eight patients did not give their permission to participate, 12 lived outside of Sivas, seven had cognitive dysfunction (understanding, speaking) therefore, the research sample was comprised of the remaining 83 patients.

Instruments

Participants were assessed using Personal Information Form (PIF), Revised Illness Perception Questionnaire (IPQ-R), and Beck Hopelessness Scale (BHS).

Personal Information Form: Personal Information form consists of 22 questions regarding the socio-demographical features and patient history-related questions on the form about the patients' age, gender, marital status, place of residence, educational status, employment status, occupation and duration of illness. This form was prepared by the researchers in light of information in the literature [1,3-4,6-8], for the purpose of determining some sociodemographic and clinical characteristics of hemodialysis patients.

Beck Hopelessness Scale: Beck Hopelessness Scale (BHS) used in the study aims to identify the negative expectations, attitudes, or hopelessness level of individuals about future.

Hopelessness was assessed with the Beck Hopelessness Scale [11], a 20-item questionnaire that assesses hopelessness by measuring participants' negative expectancies about future events. The response format for the BHS is true/false. Beck Hopelessness Scale scores can range from 0 to 20. A high score indicates a high feeling of hopelessness. Evidence indicating a coefficient α of 0.93 and a correlation of 0.74 between BHS scores and clinicians' hopelessness rating supports the reliability and validity of the BHS. The scale developed by Beck et al. was adapted for Turkey by Durak in 1994 [12].

Revised Illness Perception Questionnaire (IPQ-R): Illness perception was assessed with the well-validated Revised Illness Perception Questionnaire developed by Moss-Morris and Chalder [13]. The IPQ-R assesses nine components of illness representation in three sections. The 1st section asks about the subscale identity. In which participants are asked yes/no questions about eighteen different symptoms and if they believe these symptoms are related to being on haemodialysis.

The 2nd section consists of 38 questions address seven subscales time-line, cyclical, consequences, personal control, treatment control, coherence and emotional response. The patients rated the items on a four point scale, ranging from strongly disagree to strongly agree. The time-line dimension was assessed by six items. A higher score on this dimension indicates the perception of a chronic course of the disease. Cyclical (nature) was assessed by four items whether patients would view their illness with (as) episodes that come and go over time. The consequences dimension was assessed by six items and a higher score indicates that the patient considered their disease as having serious consequences upon their life.

While personal control dimension comprised five items and a higher score indicates the perception of a better personal control of the disease. Treatment control was assessed by five items and a higher score indicates that the patient considers, HD is efficient in controlling ESRD. Coherence is a measure of how well the patient understands his illness. It was evaluated by five items, a higher score on this dimension indicates that the patient can be considered to understand ESRD. The last dimension assessed emotional response

has six items while a higher score on this dimension indicates more intense emotional reaction to the disease. The final section focuses on the subscale causes. This scale consists of 18 possible causes for being on dialysis (e.g., lifestyle, hereditary, chance, behavior and uncertain). This scale also uses the five point Likert-type scale. The Turkish version of the IPQ-R was prepared by Kocaman and her colleagues [14].

Ethical consideration: After getting approval from Cumhuriyet University's Ethical committee, patients also had to give informed consent to be participate in the research. Independent variables that were used in this study were the component of illness perceptions while the dependent variable was hopelessness.

Data analysis: Data were analysed with SPSS for windows (Version 18.00). Mean scores and standard deviations are given as descriptive statistics. Pearson's correlation was used to analysis the relationship between illness perception and hopelessness.

Results

Table 1 shows the demographic profile of the study that 69.9% were males and 30.1 % were females. Most of the participants were married (81.9%), 50.6 graduated from primary school, 74.7 % are unemployed. Average age of the participants was found 53.88 ± 12.90 . Also in this study 31.3% had been dialyzed for 25 to 36 months, 80.7 % dialyzed >2 times a week.

Table 1: Characteristics of the study patients (n: 83)

Variables	N
Mean age in years (SD)	53.88±12.90
Gender	
Female	25 (30.1)
Male	58 (69.9)
Marital status	
Single	15 (18.1)
Married	68 (81.9)
Education level	
Illiterate	8 (9.6)
Primary School	42 (50.6)
Secondary School-High School Colleague or University	24 (28.9)
9 (10.9)	
Employment status	
Unemployed	62 (74.7)
Employment	21 (25.3)
Income Status	
Income Lower than Expenses	78 (94.0)
Income equal to or more than Expenses	5 (6.0)
Time on dialysis (yr)	
<12 ay	6 (7.2)
13-24 ay	12 (14.5)
25-36 ay	26 (31.3)
37-48 ay	21 (25.3)
>48	18 (21.7)
Dialysis frequency (weekly)	
<2 sessions	16 (19.3)
>2 sessions	67 (80.7)

Table 2 shows the scores on the IPQ-R subscales for patients. The lowest mean scores comes from the identity (Mean: 5.40, SD: 2.75) and cyclical (Mean: 12.27, SD: 3.25). It was found out that mean hopelessness scores of the participants was 8.7 ± 5.3 over 20.

Relationship between the dimensions of Illness perception and hopelessness is shown in **Table 3**. There was significant correlation between illness perception and hopelessness. In addition to, six components of illness perceptions via consequences, personal control, treatment control, illness coherence, emotional response and causes were significantly correlated with hopelessness except timeline, identity, cyclical (nature).

Discussion

The concept of illness perception is useful in understanding the impact of hopelessness on ESRD patients. This perception has been found to be an important determinant of behavior and has been associated with a number of important outcomes such as treatment adherence and functional recovery [15] and quality of life [4]. The aim of this study was to determine whether illness perception was related to hopelessness among end stage renal disease (ESRD) patients undergoing chronic haemodialysis (HD) treatment.

The present study has revealed that the participants' time-line dimension are high and identity subscale scores are low. Moreover, the highest score in the IPQ-R sub-dimensions belongs to time-line sub-dimension. These findings results showed that patients described their illness as chronic and perceived the symptoms of their disease as changing over time. This finding was consistent with reports in the literature [16,17]. Patients also perceived that the disease had a high impact on their life style. However, they still believed that the treatment they received could control their illness. Patients also strongly believed in personal control towards the disease and understood their illness well. In terms of emotional response, a high emotional instability was evident. Patients also described that although many causes had led to the ESRD, they experienced few symptoms.

Hemodialysis patients usually have a sense of hopelessness. This can affect their physical, mental and spiritual health, and can even be life- threatening [18]. In this study, it was found out that mean hopelessness scores of the participants was low which is consistent with earlier research [18,19]. This is sufficient reason to improve the care for this patient group, not only medically but also psychologically. Tsay et al. (2005) showed that it is possible to improve adaptive functioning in HD patients by means of group interventions such as patient education and techniques to increase the patients' feelings of mastery and competence [20]. Chronically ill patients, such as ESRD patients, experience certain negative events associated with their illness repeatedly. Such experiences increase negative expectancies and feelings of hopelessness [6,7]. The routine of dialysis treatment and varying levels of health may impact upon feelings of hopelessness. Hope is an important component that drives dialysis patients to continue treatment and that makes them feel better [5]. In the presence of a disease, it prevents the feeling of desperation and helplessness as well as helping patients to feel better and maintain the diseases treatment. In line with these findings, it is recommended that nurses should help patients to increase their hope- a crucial factor in coping with the illness. While providing care to patients who experience hopelessness, health workers should identify patients' features and personal characteristics and devise appropriate health interventions accordingly. Social support of dialysis patients from family is the most influential factor in overcoming feelings of hopelessness and loneliness [6,21]. For this reason, it is important that health workers do not ignore the social support systems of patients when evaluating their hopelessness and loneliness status.

Also, there was a statistically positive relationship between illness perception and hopelessness in this study. Although understanding how patients' perception of their illness will impact on how they cope with and adapt to their disease, only few and limited studies have been carried out to date [16,18]. There is evidence to show that response to an event is flavored by the individual's knowledge, capabilities, life experiences, and socio-cultural background [16]. Some patients may perceive illness in wholly negative terms and define it as a freedom adversary. When illness is perceived with the sense of doom or viewed solely in terms of decline and loss, a negative experience is likely to follow. A negative perception of illness seeds

Table 2: mean scores and standard deviation of IPQ-R and BHS.

Illness perceptions	Score range	Mean (SD)
Identity	0-18	5.40 (2.75)
Time-line	6-30	22.68 (5.63)
Cyclical	4-20	12.27 (3.25)
Consequences	9-29	18.91 (5.21)
Personal control	6-30	18.72 (4.35)
Treatment control	2-25	16.91(3.23)
Illness coherence	5-25	16.01 (4.45)
Emotional response	6-27	19.78 4.59
Causes	19-95	48.53 (11.21)
BHS	0-20	8.7±5.3

IPQ-R; Revised Illness Perception Questionnaire (IPQ-R), and BHS; Beck Hopelessness Scale.

Table 3: Pearson's correlations between illness perceptions and hopelessness.

Illness perceptions	R
Identity	0.13
Time-line	0.10
Cyclical	0.21*
Consequences	0.32*
Personal control	-0.36*
Treatment control	-0.23*
Illness coherence	-0.45*
Emotional response	0.51*
Causes	0.24*

* p<0.01

unhappiness and depression. Perception improves when illness is viewed as something that occurs within a context. Viewing illness as a normal part of life allows patients to live more fully in the present, such a view seeds positive return.

In this study, good personal and treatment control together with greater understanding of their illness were associated with less hopelessness. Hemodialysis (HD) patients' level of self-care is important to their ability to manage their disease process and symptoms. Self-care behaviours include consuming an appropriate diet, taking medications regularly, limiting fluid intake, and many other activities to help them cope with symptoms and stress. When the level of self-care is inadequate serious complications can develop. Previous studies have shown that there are correlations between self-care level and adaptation to treatment, health promoting behaviours, and decreasing physical and psychological symptoms [22,23]. In a study by Bame *et al.*, 49.5% of HD patients coped inadequately with their illness and symptoms [22].

However, there was a significant correlation between consequences, emotional response and causes components with hopelessness. Patients who perceived more consequences, high emotional response and more causes of the illness were associated with greater hopelessness. Although, there are not many studies that examined the relationship between illness perception and hopelessness among ESRD but studies performed on dialysis patients and their associations with quality of life patients showed that perception of more symptoms, more consequences and lower personal control were associated with lower well-being [3,4]. The concept of illness perceptions is useful in understanding the impact of ESRD and of dialysis treatment on quality of life. Interventions aimed at providing more knowledge about ESRD and dialysis, and provision of skills to coping with the illness and its consequences may decrease hopelessness in dialysis patients.

This study stressed on the importance of how illness perception determines the HD patients' hopelessness. The way the patients feels and believes regarding one self, the disease and also the treatment will usually affect his or her life. Additionally, the relationship between the components of illness and hopelessness provide support for pursuing further examination of the holistic outcomes in persons with ESRD patients undergoing haemodialysis. The studies suggest that by identifying patients' beliefs about an illness and its treatment, it might be possible to obtain more insight into the (mal-) adaptive responses to the illness [24,25]. Subsequently, this can provide a basis for developing interventions aimed at altering patients' perceptions to improve adaptive functioning. Petrie, Cameron, Ellis, Buick and Weinman (2002) observed that patients with myocardial infarction (MI) demonstrated better functional outcomes after MI following an individualized in-hospital intervention designed to change patients' illness perceptions [26].

Acknowledgement

We thank Dr. Ziyet Çınar, Department of Biostatistics, Cumhuriyet University for her help in analyzing the data.

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Citation: Mollaoglu M, Candan F, Mollaoglu M (2016) Illness Perception and Hopelessness in Hemodialysis. *Arch Clin Nephrol* 2(1): 044-048.