

Comparison of Saudi Arabian hemodialysis and peritoneal dialysis patients' illness perceptions

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ABSTRACT

The clinical outcome of patients with end-stage renal disease (ESRD) may differ according to their beliefs concerning their illness and its treatment. Both the disease itself and negative perceptions of the illness may increase patients' morbidity and mortality. This study aims to compare hemodialysis (HD) and peritoneal dialysis (PD) patients' illness perceptions and their related factors. This cross-sectional comparative study was conducted in five dialysis centers. After excluding patients with psychiatric comorbidities, 342 stable dialysis patients (HD, $n = 267$; PD, $n = 75$) completed a demographic questionnaire and the Revised Illness Perception Questionnaire (IPQ-R). The data were analyzed using *t*-tests and ANOVAs. Out of the 342 patients, 53.8% were male and 46.2% were female. Their mean age was 46.1 ± 16.5 years. Compared to the HD patients, the PD patients perceived their illness to be significantly less chronic ($p = .029$) and more controllable, whether through personal or treatment control ($p = .012$, $p = .017$). Patients' most common cause of attributions were stress, worry, or poor past medical care. PD showed an advantage over HD in terms of perceptions of ESRD chronicity and controllability. Intervention programs targeting illness perception are needed to support dialysis patients.

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Introduction

Life on dialysis can be challenging because of the dietary restrictions and the necessity of maintaining a treatment schedule.^{1,2} The high illness burden experienced by patients who regularly require dialysis can be further aggravated by various related social (e.g., marital problems) and financial stressors, in addition to functional deficits, limited activities, and treatment-related problems, all of which compromise psychosocial wellbeing and increase emotional distress.^{1–3} Consequently, patients with ESRD tend to develop a specific pattern of illness-related beliefs and opinions that determine their degree of understanding it (i.e., their illness perception) and the way in which they respond to it.^{4–6} The illness perceptions of patients with chronic illness have become a topic of increasing research interest over the past decade.^{3,7,8} This phenomenon is perhaps best described by the Self-Regulatory Model (SRM), which proposes that individuals have mental representations of illnesses, and when a change in physical health occurs, they spontaneously interpret their symptoms

and generate a hypothesis as to the nature of their illness. The characteristics of an individual's illness representations affect his or her ways of coping or controlling the symptoms.^{9,10} The SRM considers patients' current and past illness experiences.¹¹ Thus, the clinical outcomes for patients with chronic illness can differ according to their beliefs about their illness and its treatment;¹² consequently, the identification of such beliefs might provide a better understanding of patients' adaptive or maladaptive responses to the illness. This, in turn, could provide a basis for interventions aimed at improving adaptive functioning by altering patients' perceptions.³

Relatively little is known about the illness perceptions of dialysis patients of either modality.¹³ Most information relates to HD patients. HD patients tend to believe strongly in the chronicity of their illness, they understand it quite well, and believe their actions may influence it.^{6,12} Additionally, HD patients are often angry or frustrated with their illness, as reflected in the high emotional representation scores.¹² The two aforementioned studies did not look at PD patients; therefore,

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we are unable to precisely pinpoint the differences between these two groups of patients. Exploration of patients' illness perceptions could help physicians tailor treatment plans to improve patient health. In addition, it would be helpful to clarify whether there are differences in perception between the two dialysis modalities or between different health centers in Jeddah. This knowledge would aid decision makers in improving their healthcare services and, in so doing, would help patients achieve more positive illness perceptions. The aim of this study was to confirm that illness perceptions differed by dialysis modality.

Materials and methods

Study design and population

This cross-sectional comparative study was conducted with participants from five dialysis centers in Jeddah that provide both HD and PD: King Fahad Hospital (KFH), King Abdulaziz Hospital (KAH), King Faisal Specialist Hospital (KFSH), King Fahad Armed Forces Hospital (KFAFH), and King Abdulaziz University Hospital (KAUH).

The inclusion criteria were as follows: having stable health, being over 18 years of age, willing to participate, and having completed at least three months of dialysis. The only exclusion criterion was having a psychiatric comorbidity.

Sampling

The participants were stratified first by treatment modality, thus forming the HD and PD strata. Then, proportionate sampling was performed within each stratum. The calculated sample size was $n = 416$. In each center, patients were sorted alphabetically in tables at each dialysis session to ensure homogeneity. Then, using simple random sampling, the participants were selected according to the sample size of each stratum in each dialysis center.

Measures

The demographic information assessed comprised age, gender, occupation, marital status, and educational level. The well-validated IPQ-R questionnaire was used in conjunction with this demographic information.¹⁴ Currently, the IPQ-R is the most common tool used to assess illness perceptions among patients with chronic diseases.¹⁵ It is an 84-item self-reported instrument designed to provide a quantitative assessment of the

various illness perception domains. It is divided into three sections, with nine subscales.¹⁶

The first section comprises one subscale, identity, which is concerned with symptoms associated with patient condition. The patients were asked if they had experienced 14 commonly occurring symptoms since the onset of their illness, and if they believed these symptoms to be related to their current illness. The identity score subscale was the number of yes-rated items.^{16,17}

The second section of the IPQ-R consists of 38 items distributed over seven subscales: timeline acute/chronic, timeline cyclical, consequences, personal control, treatment control, illness coherence, and emotional representations. Questions in this section were modified by adding the term "ESRD" after the word "illness" to clarify the topic for the participants. The participants rated the items on a five-point Likert scale, with responses ranging from 1 ("strongly disagree") to 5 ("strongly agree"). The sum of the item responses for each subscale was the overall score of the subscale. Of the 38 items, 13 were reverse scored (IP1, IP4, IP8, IP15, IP17, IP18, IP19, IP23, IP24, IP25, IP26, IP27, and IP36).¹⁶

High scores on the timeline (acute/chronic and cyclical), consequences, and emotional representations subscales indicated a more negative perception of the illness. In other words, patients who viewed their illnesses as chronic and cyclical in nature believed them to be associated with serious outcomes and had strong emotional reactions to them. High scores on the personal control, treatment control, and coherence subscales indicated more positive perceptions concerning the controllability and comprehensibility of the illness.¹⁸ The third section of the IPQ-R consists of one (causal) subscale, which seeks to assess 18 possible causes the patients might attribute to their current illnesses. It uses the same Likert-type scale as in the second section. Each item (cause) is scored separately by computing its mean. Higher mean item scores indicate that the cause is more commonly identified among the patients.

The IPQ-R was translated into Arabic using standard forward-backward translation by four independent authorized translation offices. Three of them were assigned to translate the original English version into Arabic. The final Arabic version was the result of a modification of some of the terms to enhance cultural suitability. The backward translation was done by the fourth authorized translation office.

Procedure

In each dialysis center, patients were selected by simple random sampling, according to the above-mentioned

inclusion and exclusion criteria. Selected patients completed the questionnaires after being given a full explanation of the study purpose and information on how to complete the questionnaires properly.

Ethical considerations

Permission to use the validated questionnaires was obtained before the study commenced. I obtained permission via email to translate and use the IPQ-R from its original developer, Professor Rona Moss-Morris.¹⁴ This study was approved by each center's IRB committee. The participants were told that all their information would be kept confidential and would be used only for scientific research purposes.

Statistical analysis

Descriptive statistics concerning age, gender, marital status, occupation, and education level were calculated for all dialysis patients. The mean scores and standard deviations of the nine subscales of the IPQ-R were calculated for all dialysis patients and for the groups, according to dialysis modality. Independent *t*-tests were used to compare the mean IPQ-R subscale scores by dialysis modality.

Results

The overall participant response rate was 82.2%. The response rates per center, as shown in Table 1, ranged from 76.5% at KFAFH to 100% at KFH for the HD patients, and from 50% at KAH to 73.1% at KFH for the PD patients.

The participant demographic profiles were compared among both dialysis modalities, as shown in Table 2. Of the 342 patients, 53.8% were male, and 46.2% were female. Their mean age was 46.1 ± 16.5 years. More than half (56.1%) of them were single, 28.3% were married, and 15.6% were divorced or widowed. Regarding educational level, more than half (55%) of the participants had less than a secondary school education, and 22.5% were illiterate. Of the 291 patients who reported their occupations, almost three-quarters (74.2%) were unemployed.

The scores on the IPQ-R, as shown in Table 3, indicate that timeline cyclical (3.42 ± 0.72) had the highest scores, followed by consequences (3.36 ± 0.79) and illness coherence (3.35 ± 0.80). In other words, most participants perceived their symptoms to change over time. They also believed their diseases affected their lives, and they understood their conditions relatively well. Moreover, based on the scores of the personal

Table 1. Participant response rates by center.

Center	Estimated sample size		Completed questionnaires		Response rate	
	HD	PD	HD	PD	HD	PD
KFH	140	26	140	19	100%	73.1%
KAH	21	24	18	12	85.7%	50%
KFSH	38	21	35	13	92.1%	61.9%
KFAFH	68	40	52	21	76.5%	52.5%
KAUH	24	14	22	10	91.7%	71.4%

KFH: King Fahad Hospital; KAH: King Abdulaziz Hospital; KFSH: King Faisal Specialist Hospital; KFAFH: King Fahad Armed Forces Hospital; KAUH: King Abdulaziz University Hospital; HD: hemodialysis; PD: peritoneal dialysis.

Table 2. Participants' personal and professional characteristics.

Characteristics	Dialysis modality		
	HD n(%)	PD n(%)	Total N(%)
Gender			
Male	(55.8) 149	(46.7) 35	(53.8) 184
Female	(44.2) 118	(53.3) 40	(46.2) 158
Marital status			
Married	151 (57.2)	39 (52)	190 (56.1)
Single	72 (27.3)	24 (32)	96 (28.3)
Divorced	15 (5.7)	4 (5.3)	19 (5.6)
Widowed	26 (9.8)	8 (10.7)	34 (10)
Education level			
Illiterate	(24.7) 65	(14.7) 11	(22.5) 76
Just read and write	(5.3) 14	(9.3) 7	(6.2) 21
Primary school	(14.1) 37	(8.0) 6	(12.7) 43
Intermediate school	(12.9) 34	(16.0) 12	(13.6) 46
High school	(24.7) 65	(28) 21	(25.4) 86
Bachelor's degree or higher	(18.3) 48	(24) 18	(19.5) 66
Age (Mean \pm SD)	16.5 \pm 45.8	14.2 \pm 47.2	46.1 \pm 16.5
Occupation			
Unemployed	174 (75.7)	45 (69.2)	219 (74.2)
Employed	56 (24.3)	20 (30.8)	76 (25.8)

SD: standard deviation.

Table 3. Mean IPQ-R scores and standard deviations.

Subscale	Item means (SDs)	Score range	Mean (SD)	%
Identity		0–14	6.90 (3.29)	49.3%
Timeline acute/chronic	3.03 (0.79)	6–30	18.2 (4.77)	60.7%
Timeline cyclical	3.42 (0.72)	4–20	13.7 (2.87)	68.5%
Consequences	3.36 (0.79)	6–30	20.2 (4.71)	67.3%
Personal control	3.24 (0.52)	6–30	19.5 (3.14)	64.9%
Treatment control	3.32 (0.49)	5–25	16.6 (2.43)	66.5%
Illness coherence	3.35 (0.80)	5–25	16.7 (3.99)	67.0%
Emotional representation	3.28 (1.00)	6–30	19.7 (6.02)	65.6%

control (3.24 ± 0.52), treatment control (3.32 ± 0.49), and emotional representation (3.28 ± 1.00) subscales, the participants believed they had the ability to play a role in controlling their symptoms, and that their illnesses could be treated; however, they showed unstable emotional responses. On the other hand, the lowest score was for the identity subscale, which indicated patients believed only some of their symptoms could be attributed to their illness. They also perceived their illness as relatively chronic, as per a timeline acute/chronic score of 3.03 ± 0.79 .

Table 4. Comparison of IPQ-R scores by dialysis modality.

Subscale	Dialysis modality		<i>p</i> ^a
	HD Mean (SD)	PD Mean (SD)	
Identity	7.07 (3.35)	6.32 (3.01)	.082
Timeline acute/chronic	18.5 (4.71)	17.1 (4.84)	.029
Timeline cyclical	13.7 (2.91)	13.7 (2.77)	.965
Consequences	20.2 (4.79)	20.0 (4.44)	.642
Personal control	19.2 (3.19)	20.3 (2.82)	.012
Treatment control	16.5 (2.35)	17.2 (2.60)	.017
Illness coherence	16.5 (4.05)	17.7 (3.63)	.017
Emotional representations	19.8 (6.01)	19.4 (6.08)	.608

^aBased on independent *t*-tests.

Table 5. Comparison of IPQ-R causal items by dialysis modality.

Item	HD Mean(SD)	PD Mean(SD)	<i>p</i> ^a
Stress or worry	3.17 (1.28)	3.21 (1.15)	.784
Hereditary	2.31 (1.19)	2.37 (1.24)	.709
A germ or virus	2.37 (1.03)	2.28 (1.09)	.507
Diet or eating habits	2.87 (1.19)	3.07 (1.15)	.211
Chance or bad luck	2.76 (1.17)	2.61 (1.18)	.339
Poor medical care in my past	3.16 (1.24)	3.31 (1.25)	.383
Pollution in the environment	2.97 (1.20)	2.73 (1.22)	.135
My own behavior	2.53 (1.13)	2.57 (1.14)	.779
My mental attitude	2.41 (1.13)	2.45 (1.19)	.763
Family problems or worries	2.37 (1.21)	2.39 (1.28)	.903
Overwork	2.45 (1.17)	2.53 (1.21)	.603
My emotional state	2.52 (1.25)	2.52 (1.30)	.997
Aging	2.41 (1.17)	2.65 (1.34)	.127
Alcohol	1.88 (1.09)	2.12 (1.07)	.555
Smoking	2.14 (1.23)	2.12 (1.25)	.890
Accident or injury	2.13 (1.16)	2.21 (1.17)	.588
My personality	2.11 (0.99)	2.05 (1.17)	.642
Altered immunity	2.61 (1.24)	2.76 (1.20)	.366

^aBased on independent *t*-tests.

In comparing illness perceptions by dialysis modality (Table 4), HD patients were significantly more likely to believe in the chronicity of their illness than were PD patients, according to their higher timeline acute/chronic scores (18.5 ± 4.71 vs. 17.1 ± 4.84). On the other hand, PD patients believed more in their ability to control their illness, and that their illness could be controlled by treatment, than did the HD patients, as per the higher scores in personal (19.2 ± 3.19 vs. 20.3 ± 2.82) and treatment control (16.5 ± 2.35 vs. 17.2 ± 2.60), respectively. The other subscales of the IPQ-R did not significantly differ between the modalities.

A comparison of the causal items revealed no significant differences between the modalities (Table 5), indicating all the patients believed their illnesses had the same causes. The most common causes attributed by the patients were stress or worry, and poor past medical care; the least attributed causes were alcohol, smoking, and the patient's personality.

Discussion

According to the participants' IPQ-R scores, they did not attribute a high proportion of their symptoms

to their illnesses. Furthermore, they generally experienced ESRD as a chronic illness with varying symptoms over time that negatively influenced their lives. They were also emotionally unstable, although they felt their illness was controllable both by their own actions and through treatment.

Compared to other chronic illnesses such as osteoarthritis, rheumatoid arthritis, heart failure, vasculitis, and cystic fibrosis, dialysis patients reported average IPQ-R scores;^{17,19–22} however, they experienced relatively more symptom variation over time than did patients with heart failure, vasculitis, or cystic fibrosis. In addition, they had stronger emotional representations than did people with heart failure, vasculitis, or osteoarthritis. These differences might be explained by how ESRD patients require dialysis on an almost daily basis, which doubtlessly affects their symptoms and emotions. For instance, muscle weakness is the most frequent and distressing treatment-related symptom among HD patients,^{23,24} and it is possible patients with ESRD may experience stronger emotional upset due to such treatment-related symptoms than do patients with other illnesses. They might also be more concerned about the arterio-venous fistula, which is created as an access point for dialysis needles, as it might be noticeable to others and its presence is a reminder to them of their continuous need for dialysis.²⁴

Moreover, the results indicate that PD patients perceived their illness as significantly less chronic and more controllable than did the HD patients. This might be logical, given that PD patients agree to receive the treatment despite the overall low percentage of medical professionals who are reliant on it, whereas the HD patients preferred dialysis under supervision. Patients are generally more satisfied with their treatment if they are involved in the selection of the treatment modality.²⁵ PD's advantage in terms of personal control is consistent with Timmers et al.'s³ findings. In terms of treatment consequences, Jansen et al.²⁶ concluded that the HD patients perceived more treatment consequences than did the PD patients, which was inconsistent with the findings of the current study. This discrepancy might be due to the PD group's low sample size ($n = 48$). Generally, these findings confirm the importance of patients' beliefs concerning their illness and symptoms in determining their overall health. This suggests it is important to develop an illness perception intervention for patients during dialysis sessions or follow-up visits. Interventions focusing on illness perceptions have been described recently for patients with ESRD and other chronic diseases.^{27,28} The program for ESRD patients was based on SRM theory, and was aimed at maintaining a sense of autonomy among the

patients and increasing their activities through paid work.

Limitations and strengths

As a comparative study, the major limitation of the current research was a small PD patient sample size, since it did not allow for proportionate sampling between the two strata (HD and PD). This, however, was expected because of the low percentage of PD patients in Saudi Arabia. On the other hand, the strength of the present study was its inclusiveness of both treatment modalities, as well as its utilization of multiple centers.

The study results indicated that PD has advantages over HD in terms of the perception of ESRD chronicity and controllability. In addition, it confirms the need for intervention programs targeting illness perception, both to support dialysis patients in their illness and to improve their health. However, due to variations in the relationships between illness perception domains, it is more suitable to deal with each domain separately.

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Disclosure statement

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this paper.

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