

## Assess the Illness Perception and Treatment Adherence among Patients with End-Stage Renal Disease

### Abstract

**Background:** Chronic Renal Disease (CRD) complications had a sizeable effect on the patients. This study evaluates illness perception, treatment adherence and clinical outcomes of patients with End-Stage Renal Disease (ESRD) and finds an association with variables. **Materials and Methods:** A descriptive cross-sectional study was conducted among patients at Sri Ramachandra Institute of Higher Education and Research, Chennai, India during October and November 2017. Data were collected through interviews of each patient separately before hemodialysis. Demographic, clinical variables, identity dimension and control dimension of patients were assessed. Adherence behaviours were measured using ESRD-AQ in four dimensions. Clinical outcome was evaluated based on biochemical parameters. The collected data were analysed by percentage distribution and regression analysis. **Results:** The study had 120 patients with ESRD with male to female ratio of 2:1 where the majority (35.80%) were in the age group of 51–60. The identity dimension mean (SD) score was 10.80 (1.51). Under the control dimension mean scores were higher in the sub-dimension of emotional representations, consequences and personal control. Among 120 patients, 63 (52.50%) had adherence to dietary restriction. A statistically significant association was observed between timeline with Body Mass Index (BMI) ( $F_3 = 4.81, p = 0.003$ ) and comorbidity ( $F_2 = 2.99, p = 0.022$ ). **Conclusions:** The higher mean score in the sub-dimensions of emotional representations indicates a higher degree of emotional distress due to low adherence to prescribed medications.

**Keywords:** Adherence, chronic renal insufficiency, efficacy, illness behaviours, perception

### Introduction

There is a rising incidence of Chronic Renal Disease (CRD) that is possible to pretense major problems for healthcare and the economy in future years.<sup>[1]</sup> Renal failure is linked with high mortality and associated with cardiovascular disease now recognised as a major medical problem worldwide. In addition, there is a rising incidence of Chronic Kidney Disease (CKD) that is likely to pose major problems for both healthcare and the economy in future years.<sup>[2]</sup> According to Mei-Chen *et al.* 2016, 361 out of every million people in Taiwan suffer from CKD, an incidence rate ranking second highest in the world.<sup>[3]</sup> The studies carried out in the Netherlands and the United States have shown CKD (stage 1–5) prevalence rates of 10% and 13%, respectively.<sup>[4,5]</sup> In India, age-adjusted incidence rate of End-Stage Renal Disease (EDRD) is 229 per million population and one of ten leading causes of death.<sup>[4]</sup> In the US adults aged 18 years

or older, the main reported causes of new cases of ESRD were diabetes and high blood pressure.<sup>[5-7]</sup> Reduced daily physical activity and physical performance with the depression of Maintenance Hemo dialysis patient are associated with increased hospitalization and enhanced mortality rates.<sup>[8]</sup> The increasing rate of chronic kidney disease epidemic and increasing ESRD remains grave confront for many developing countries due to unavailability of high-end sophisticated treatment facilities.<sup>[9-11]</sup> Regular dialysis is provided to patients to maintain a healthy life, which is the only aspect of the treatment regimen that needs to be done throughout the patient's life. Illness perception is used to define beliefs of a patient about own health problems. Such perception has been shown to affect coping in the context of a physical or mental illness.<sup>[12]</sup> Diabetic nephropathy and underlying cardiovascular diseases are the leading cause for ESRD.

Sekar Suganthi<sup>1</sup>,  
Arjunan Porkodi<sup>2</sup>,  
Poomalai Geetha<sup>3</sup>

<sup>1</sup>Faculty of Nursing, Sri Ramachandra Institute of Higher Education and Research (Deemed to be University), Porur, Chennai, Tamil Nadu, India, <sup>2</sup>Department of Medical and Surgical Nursing, Sri Ramachandra Institute of Higher Education and Research (Deemed to be University), Porur, Chennai, Tamil Nadu, India, <sup>3</sup>Department of Nursing Foundation, Sri Ramachandra Institute of Higher Education and Research (Deemed to be University), Porur, Chennai, Tamil Nadu, India

### Address for correspondence:

Dr. Arjunan Porkodi,  
Faculty of Nursing,  
Sri Ramachandra Medical  
College and Research Institute  
(Deemed to be University),  
Porur, Chennai - 600 116,  
Tamil Nadu, India.  
E-mail: [porkodi@sriramachandra.edu.in](mailto:porkodi@sriramachandra.edu.in)

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To follow dietary and fluid restrictions accompanied by an extensive list of medications, patients' self-determination and self-care behaviours become crucial for the organisation of ESRD.<sup>[13]</sup> Assessing adherence among hemodialysis patients will allow healthcare providers to implement interventional methods to minimise the health and economic consequences of non-adherence.<sup>[3,11,12]</sup> Failure of adherence in HD patients can lead to increase morbidity, mortality, cost and burden on the healthcare system.

Earlier Sak *et al.* in 2014 studied 83 HD patients, showing a significant relationship between hopelessness and illness perception. HD patients believing that their illness was chronic and due to illness stress-worry occurs.<sup>[14]</sup> Jayanti *et al.* (2014) studied a group of 150 patients on chronic Hemodialysis, exhibits the interdependence of psychological illness perception and need for social support with the level of urea before dialysis among ESRD patients.<sup>[15]</sup> Kim *et al.* (2010) studied behaviours of outpatient at dialysis centers in the USA and represented stronger overall negative perceptions, correlations with adherence behaviours and clinical outcomes.<sup>[16]</sup> Higher scores on the ESRD-AQ denote higher adherence to the measured behaviour.<sup>[17-19]</sup> This present study analyses the effect of illness perception, treatment adherence and determine clinical outcomes in ESRD among patients and finds the association with selected background variables in the dialysis ward at Sri Ramachandra Medical Center, Porur, Chennai.

## Materials and Methods

A descriptive cross-sectional study was conducted during October and November 2017 among ESRD patients. The sample size for the study was determined based on a previous study<sup>[16]</sup> using power analysis with Z Value corresponding to a 95% level of significance (1.96), wherein S = estimated sample size, d = absolute precision (10%). The 120 participants were selected for the study according to inclusion criteria using a convenience sampling method. Both male and female candidates above 18 years of age subjected to hemodialysis at least 2 or 3 times a week were included in the study while patients receiving peritoneal dialysis, admitted for emergency hemodialysis were excluded from the study. Participants were randomly assigned to a control and intervention group using colour cards. Each subject was interviewed using various instruments separately before the hemodialysis in the F2 dialysis ward. The interview lasted for 20 to 30 min.

The instrument consisted of four parts as described below: Demographic variables had two parts which included part 1 containing information of demographic variables such as age, gender, education, occupation, income, and residence while part 2 contained information on clinical variables such as duration of illness, number of dialyses, dietary patterns, Body Mass Index (BMI), comorbid illness, medications and family history of renal disease. In this

study, under Illness Perception Questionnaire-Revised (IPQ-R), the identity dimension and the control dimension were assessed as described in earlier studies.<sup>[20]</sup> The causal dimension was not related to ESRD, not added for the study during data collection. The identity dimension was scored in a yes = 1, or no = 0 format that addresses the number of symptoms attributed to illness. The identity dimension had 14 (maximum score 14) items on physical symptoms attributed to illness and high scores of identity indicate complaining of more physical symptoms. Control dimension which has 7 sub-dimensions were scored based on a five-point Likert scale from strongly disagree to strongly agree (strongly disagree = 1, disagree = 2, neither agree nor disagree = 3, agree = 4, strongly agree = 5). Adherence behaviours were measured using the ESRD-AQ in four dimensions that include HD attendance, fluid restrictions, medication use, diet restrictions and recommendations.<sup>[16]</sup> ESRD-AQ was assessed based on the combination of Likert scale and multiple-choice, as well as 'a yes = 1, or no = 0' answer format. Higher scores on the ESRD-AQ denote higher adherence to the measured behaviour. The reliability of the instrument was established by test and retest method using Cronbach alpha method and *r* was found to be 0.78 and 0.79, respectively.

The clinical status of patients was determined based on the results of the last 3 months biochemical markers such as hemoglobin level, blood urea nitrogen, serum creatinine and viral serology such as HBsAg, anti-HCV and HIV. These results determined the patients' health status and indicated whether or not they are having any infectious disease or organ function disability. Study data were analysed through the statistical package for social science (SPSS Ver. 19, SPSS Inc., IBM Corporation, Chicago, IL, USA) program. Mean (SD), frequency and percentage were used to assess the patient's demographic and clinical variables. Inferential Statistics "ANOVA" was used to signify the association of illness perception and treatment adherence with variables. Pearson correlation was utilised to determine the relationship between illness perceptions and treatment adherence with background and clinical variables.  $p < 0.05$  was considered to be significant.

## Ethical considerations

This prospective study was approved by the Institutional Ethical Committee based [CSP/17/June/59/185] on the Indian Council of Medical Research guidelines of biomedical research in human beings. Informed consent was obtained from the participants with the option to withdraw from the study at any time.

## Result

Males dominated the study population with a ratio of 2:1 and the majority (43 [35.80%]) were from the age group between 51–60 years. Almost 90% had formal education up to primary school and close to 45% of the patient's

**Table 1: Frequency and percentage distribution of the demographic and clinical variables among patients with End-Stage Renal Disease (ESRD) variables**

Demographic Variables	N (%)	Clinical variables	N (%)
Age [in years]		Duration of illness in years	
18-30	7.00 (5.80)	<1	59.00 (49.20)
31-40	15.00 (13.00)	3-Jan	48.00 (40.00)
41-50	23.00 (19.00)	5-Mar	4.00 (3.30)
51-60	43.00 (36.00)	>5	9.00 (7.50)
61-70	32.00 (27.00)	Number of dialysis per week	
Gender		2	86.00 (77.70)
Male	81.00 (68.00)	3	34.00 (28.30)
Female	39.00 (33.00)	Type of diet	
Education		Vegetarian	10.00 (8.30)
No formal Education	8.00 (6.70)	Non-Vegetarian	105.00 (87.50)
Primary	40.00 (33.00)	Mixed diet	5.00 (4.20)
High school	37.00 (31.00)	Body Mass Index	
Diploma	7.00 (5.80)	<18.5	3.00 (2.50)
Graduation	23.00 (19.00)	18.5-24.9	50.00 (41.70)
Postgraduation	5.00 (4.20)	25-30	43.00 (35.80)
Occupation		>30	24.00 (20.00)
Unemployed	33.00 (28.00)	Comorbid illness	
Government employee	29.00 (24.00)	Diabetes Mellitus	24.00 (20.40)
Private sector employee	27.00 (23.00)	Hypertension	92.00 (76.70)
Self-employed	31.00 (26.00)	Bronchial asthma	1.00 (0.80)
Family monthly income [Rs./month]		Jaundice	2.00 (1.70)
2501-5000	12.00 (10.00)	Cardiovascular disease	1.00 (0.80)
5001-7500	2.00 (1.70)	Family history of renal disease	
7501-10000	24.00 (20.00)	No	113.00 (94.20)
10001-12500	27.00 (23.00)	Yes	7.00 (5.80)
>12500	55.00 (26.00)		
Place of living			
Rural	28.00 (23.00)		
Urban	39.00 (33.00)		
Semi-Urban	53.00 (44.00)		

family monthly income was >10000 INR. Around 49.20% of them had ESRD for <1 year and 86 (71.70%) of the patients received hemodialysis twice a week. Around 92 (76.70%) of the patients had hypertension and it was found that 113 (94.20%) patients had no family history of renal disease [Table 1].

The frequent illness perceptions among patients were pain, breathlessness, weight loss, stiffening of joints, stomach upset, sleep difficulties, dizziness and loss of stamina which were seen in more than 60% of the study population. Identity dimension means (SD) score was 10.80 (1.51) With regard to control dimension, mean (SD) scores were higher in the dimensions of emotional representations (22.96 ([2.78]) and consequences (21.4 ([2.66])). Around 100 (83.30%) study participants were regular to Hemodialysis (HD) session and 108 (90%) of them had no episode of shortening their HD. The majority (83.30%) of the patient adhered to attendance for HD, and more than half patients 63 (52.50%) had adherence to dietary restriction. An episode of shortening

HD was noticed in 90% study population with mean (SD) score of 1.30 (1.21) days. The number of patients adheres to medication, fluid was 49 (40.80%) and 55 (45.80%), respectively. The average hemoglobin was 9.68 (1.76) g/mL, blood urea nitrogen was 51.74 (24.70) mg/dL and serum creatinine was 7.63 (2.28) mg/dL. Serology test results revealed that 106 (88.30%) patients were negative for HBsAg, 92 (76.70%) were Hepatitis C virus (HCV) negative and 82 (68.30%) patients were HIV negative [Table 2].

Study results found a negative correlation between the identity dimension of illness perceptions and treatment adherence. There was a statistically considerable positive correlation between timeline cyclical and treatment adherence, illness coherence and treatment adherence among patients with ESRD [Table 3]. A statistically significant association between timeline (cyclical) with BMI ( $F_3 = 4.84, p = 0.003$ ) and with comorbidity ( $F_2 = 2.99, p = 0.022$ ). Also, a significant association between consequences and comorbidity illness was seen

**Table 2: Frequency and percentage distribution of illness perceptions among patients with ESRD**

Identity dimension	Yes N (%)	No N (%)
Pain	117.00 (97.50)	3.00 (2.50)
Sore throat	62.00 (51.70)	58.00 (48.30)
Nausea	49.00 (40.80)	71.00 (59.20)
Breathlessness	95.00 (79.20)	25.00 (20.80)
Weight loss	111.00 (92.50)	9.00 (7.50)
Fatigue	108.00 (90.00)	12.00 (10.00)
Stiff joints	91.00 (75.80)	29.00 (24.20)
Sore eyes	69.00 (57.50)	51.00 (42.50)
Wheeziness	69.00 (57.50)	51.00 (42.50)
Headaches	78.00 (65.00)	42.00 (35.00)
Upset stomach	103.00 (85.80)	17.00 (14.20)
Sleep difficulties	112.00 (93.30)	8.00 (6.70)
Dizziness	117.00 (97.50)	3.00 (2.50)
Loss of stamina	115.00 (95.80)	5.00 (4.20)
ESRD-AQ	N (%)	Mean (SD)
1. HD attendance	100.00 (83.30)	1.24 (0.66)
1a. Episode of shortening HD	108.00 (90.00)	1.30 (1.21)
1b. Duration of shortening HD	114.00 (95.00)	1.10 (0.49)
2. Adherence to medication	49.00 (40.80)	1.85 (0.86)
3. Adherence to fluid restriction	55.00 (45.80)	1.73 (0.79)
4. Adherence to dietary restriction	63.00 (52.50)	2.00 (0.82)
Illness perception	Possible score range	Mean (SD)
Identity Dimension <sup>[14]</sup>	0-14	10.80 (1.51)
Control Dimension	-	-
Timeline[acute/chronic] <sup>[6]</sup>	6-30	17.75 (2.92)
Timeline [cyclical] <sup>[4]</sup>	4-20	14.46 (2.39)
Consequences <sup>[6]</sup>	6-30	21.4 (2.66)
Personal control <sup>[6]</sup>	6-30	20.21 (3.71)
Treatment control <sup>[5]</sup>	5-25	14.77 (3.53)
Illness coherence <sup>[5]</sup>	5-25	16.97 (3.10)
Emotional representations <sup>[6]</sup>	6-30	22.96 (2.78)

**Table 3: Relationship between the illness perceptions, control dimension and treatment adherence among patients with ESRD**

Variables	r	p
Identity dimension and treatment adherence	0.37	-0.82
Control dimension		
Timeline[Acute/Chronic] and treatment adherence	0.17	0.125
Timeline[cyclical] and treatment adherence	0.81	0.023
Consequences and treatment adherence	0.46	0.069
Personal and treatment adherence	0.38	-0.81
Treatment control and treatment adherence	0.44	0.071
Illness coherence and treatment adherence	0.79	0.024
Emotional representations and treatment adherence	0.04	0.186

Pearson correlation was utilized to determine the relationship of illness perceptions, and treatment adherence with variables (\* $p < 0.05$ , significant)

which was statistically significant ( $F_2 = 3.59, p = 0.009$ ). Association of personal dimension with a duration of illness ( $F_3 = 3.31, p = 0.032$ ) and the number of dialyses ( $F_2 = 5.81, p = 0.017$ ) and with comorbidity ( $F_2 = 3.64, p = 0.008$ ) was statistically significant. The illness coherence dimension with a family history of renal disease was also statistically significant ( $F_2 = 6.04, p = 0.003$ ). In addition, there was also a significant association between treatment adherence and duration of illness ( $F_3 = 3.16, p = 0.027$ ).

## Discussion

This study results supported the application of a conceptual framework based on the health promotion model by Pender in 2011.<sup>[20]</sup> In our first study objective, we found that pain and dizziness, loss of strength, sleep difficulties, weight loss and fatigue were major complications reported by the study participants and this symptom was also similarly reported earlier.<sup>[21]</sup> Under the control dimension, mean scores were higher in the sub-dimension of emotional representations, consequences mean score and personal control mean score. Emotional distress was high due to illness, high mean scores on the sub-dimension of consequences and the timeline indicated a high degree of perceptions of chronicity and unfavorable consequences of illness. In a similar finding, Lucie *et al.* (2008) stated that dialysis patients experienced a higher level of personal control and illness coherence compared with HD patients. Illness perceptions were associated with lower well-being, variances in quality of life scores, symptoms, more consequences and lower personal control.<sup>[22]</sup> These reports support those earlier studies which reported that mean scores were higher in the dimensions of the timeline (acute/chronic), consequences, personal and treatment controls and emotional perceptions indicating that most study participants understood their kidney disease was likely to be permanent rather than temporary and were aware of the seriousness of their condition.<sup>[17,21,22]</sup> In a similar kind of study peritoneal dialysis patients practised a high rate of personal control with considerably high scores of illness coherence compared with HD patients.<sup>[21]</sup> These findings were supported by a study that reported that mean scores of consequences, emotional perceptions, personal and treatment controls, dimensions of timeline (acute/chronic), were higher than scores from other dimensions.<sup>[16]</sup> For different hemodialysis status, gender, BMI, comorbidities, different stages of CKD and treatment aspect for patients having different socioeconomic status, adherence to drug therapy was found altering significantly. The socioeconomic status has a profound effect on BMI and treatment aspect which ultimately associated with hemodialysis status, comorbidities and adherence to drug therapy. Availability

to low-cost treatment and the facility would certainly help patients to overcome shortfalls in treatment adherence and future outcome. Forgetting of medication was the most common motive for non-adherence, and maximum non-adherence was for antihypertensive medications,<sup>[17]</sup> indicates if patients do not have complication they tend to forget medication. Similarly, the highest observance rate was for diet constraint and lowest adherence rate was for dialysis turnout.<sup>[22]</sup> A similar study was conducted at Egypt which reported that patients' knowledge was increased after the intervention and thereafter the adherence score was also increased after interventions.<sup>[18]</sup>

The study related to factors influencing home hemodialysis in the United States reported that the self-care HD group had a significantly higher rate of anxiety scores, depression, IPQ-R subscales, and illness coherence than those who were in the center.<sup>[15,23]</sup> A study from Iran showed that the majority of patients were non-adherence to fluid diet and the highest level of apparent support was family support.<sup>[23]</sup> A significant relationship was seen between social sustain and obedience to dietary limits similarly reported in another study among elderly hemodialysis patients above 65 years for a cohort study conducted from 2008 to 2015.<sup>[24,25]</sup> Study had the limitation that investigator was unable to collect actual data on the illness perception and treatment adherence among patients with ESRD on maintenance hemodialysis as the data was collected just before the HD in the waiting area which may inhibit their actual perceptions of their illness due to their sufferings like breathing difficulty, weight gain and tiredness. Therefore we recommended replicating the present study with large samples conducted as a comparative qualitative study between the rural and urban populations to know their lived-in experiences of a patient with ESRD.

## Conclusion

These current findings suggest that patients had physical symptoms such as pain, dizziness, loss of strength and sleep difficulties, the higher mean score in the sub-dimensions of emotional representations indicates a higher degree of emotional distress due to illness, low adherence to prescribed medications. Thus, strategies to manage physical symptoms, measures to overcome emotional distress as well as measures to improve medication obedience should be meticulously pursued in these people.

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Nil.

## Conflicts of interest

Nothing to declare.

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