



(RESEARCH ARTICLE)



## Illness perception, self-esteem and self-care management of patients on continuous ambulatory peritoneal dialysis: A cross-sectional study from a Tertiary Care Hospital in South India

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### Abstract

**Background:** Chronic diseases are those conditions that last for more than a year requiring ongoing medical attention and crippling the activities of daily living. End-stage kidney disease invites significant psychosocial stressors and demands routine adaptation. It challenges the patient with a constant fear of death, draining them physically and mentally, making them dependent on the healthcare team and having to follow complicated pharmacological regimes with dietary limitations.

**Objective:** The study was intended to assess illness perception, self-esteem, and self-care management of patients on continuous ambulatory peritoneal dialysis.

**Methodology:** Using quantitative approach, a descriptive study was undertaken for a period of six weeks in Peritoneal Dialysis unit of the Artificial Kidney Lab (AK Lab) of Christian Medical College, Vellore. A total of 63 patients were selected using total enumeration sampling technique. Data was collected using self-administered questionnaires namely Brief Illness Perception Questionnaire (B-IPQ), Current thoughts scale and Questionnaire on self-care management.

**Results:** Most of the subject's illness perception were moderately (42.86%) and severely affected (41.27%). On the whole, the subjects had higher self-esteem (mean = 71.49); however, the appearance self-esteem was rather low (19.67). All subjects had adequate self-care management.

**Conclusion:** Patients undergoing CAPD perceive their illness as a threat and they have low appearance self-esteem. On the basis of this finding, formulation of guidelines for psychological management of these patients would help them to develop coping skills.

**Keywords:** CAPD; Illness perception; Self-esteem; Self-care management; Peritoneal dialysis

### 1. Introduction

Chronic diseases are those conditions that last for more than a year requiring ongoing medical attention and crippling the activities of daily living and end stage kidney disease is one of them (1). According to the World Health Organization (WHO), End-stage kidney disease can be defined as a condition that requires renal replacement therapy to extend the life-expectancy of the affected individual (2). The worldwide estimation of persons diagnosed with end stage renal disease is 2 million, with growing annual incidence of approximately 5-7% (3). However, because of the expensive

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nature of renal replacement therapy, the treatment for End Stage Kidney Disease is more of an option for high-income countries or the developed countries compared to the low-income or the developing countries (4).

Renal replacement therapy includes hemodialysis, peritoneal dialysis, and renal transplantation (5). All of these modalities remove nitrogenous waste and excess fluid from the blood, using osmosis, diffusion and ultra-filtration across semi-permeable membranes (6). Dialysis can be done intermittently or continuously. Continuous dialysis therapy is sometimes better tolerated in unstable patients when compared to intermittent therapy as solute and fluids are gradually removed (7). The choice of this therapy depends on patient's preference, indications, availability and affordability (8).

In Peritoneal Dialysis (PD), a special solution is introduced through a permanent catheter in the lower abdomen in order to remove the waste products like urea and creatinine (9). This may either occur at regular intervals throughout the day, known as Continuous Ambulatory Peritoneal Dialysis (CAPD), or at night with the assistance of a machine, known as Automated Peritoneal Dialysis (APD) (10); if initiated, PD has to be continued lifelong or till a renal transplantation is carried out. In APD, the machines can be programmed to deliver precise volumes of PD fluid in multiple cycles throughout the night as the patient sleeps, so that, the patient's daytime routine is unaffected (11).

Despite these available treatment modalities, End-stage kidney disease invites significant psychosocial stressors and demands routine adaptation (12). It challenges the patient with a constant fear of death, draining them physically and mentally, making them dependent on the healthcare team and having to follow complicated pharmacological regimes with dietary limitations (13).

These patients require psychosocial evaluation because renal replacement therapy makes the patient socially and emotionally vulnerable (14). Dialysis interrupts the patient's routine work, school, and leisure activities resulting in anger, frustration and guilt; on the other hand, it alters body image due to energy loss, change in sexual function, vascular access surgery and catheter placement in the abdomen (15). Some patients may react to these feelings by non-adherence and noncompliance to the therapeutic regimen (8). However, some personality traits like adaptability, independence, self-control, effective coping, optimism and emotional stability improves the prognosis of these patients (13).

Research based on illness perception seems to bring out the association between patient's belief and health-related outcome. Their self-care depends on whether they believe that the illness could be controlled or cured (16). Home-based therapy in PD offers several advantages including preservation of patient autonomy, fewer visits to the hospital and improved quality of life with social and professional rehabilitation compared to patients on hemodialysis (17). It is a self-care modality, allowing patients to self-manage their own treatment and care. A meta-analysis on the factors affecting self-care management behavior revealed that personal health beliefs, perceived control over the illness and symptoms can either be a facilitator or barrier to self-care management. Illness perception helps them develop responsibility towards their own health (18).

An individual living with chronic illness often experiences low self-esteem, a poor sense of personal worth, and low self-efficacy, a diminished sense of one's capacity to influence behavioral outcomes. This can significantly affect the patient's wellbeing resulting in health related outcomes like ineffective coping, hopelessness, poor self-care, an increased risk of complications. Therefore, it becomes necessary to promote one's self-esteem to improve health (19).

This descriptive study evaluates the illness perception, self-esteem and self-care management of patients undergoing PD, as it is a self-care modality.

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## **2. Material and methods**

### **2.1. Study type and setting**

A quantitative, descriptive research design was used to assess illness perception, self-esteem and self-care management of patients on Continuous Ambulatory Peritoneal Dialysis. The study was conducted in PD unit of the Artificial Kidney Lab (AK Lab) of Christian Medical College and hospital, Vellore. CMCH is a 2964 bedded multi-specialty hospital, providing tertiary care to a large population consisting of Indian citizens and foreigners. It is well equipped with advanced diagnostic and treatment modalities providing competent inpatient, outpatient and palliative care services.

AK lab is a highly specialized well equipped 33 bedded unit, with PD out-patient unit. Hemodialysis and CAPD are done on all days except Sunday. Approximately 70 - 80 CAPD patients attend the PD out-patient unit every month on Wednesday for training, treatment and follow up.

## 2.2. Sample size and sampling technique

The sample size was calculated using the expected proportion of self-esteem to be 27% (20), with the precision of 10% and the desired confidence level was set at 95%. Using these criteria the sample size was found to be 76.

Total enumeration sampling technique was used for the study due to limited availability of samples. The Sample consisted of patients on CAPD, who fulfilled the inclusion criteria. Patients who are 18 years and above, practicing CAPD for >3 months and can read and understand English or Hindi or Tamil are included in the study. Patients with psychiatric illness and critical illness were excluded from the study.

## 3. Results

**Table 1** Distribution of subjects based on their socio-demographic variables (N=63)

S. no	Variables	Frequency	Percentage (%)
1	Age		
	55 and less	35	55.6
	Above 55	28	44.4
2	Sex		
	Male	39	61.9
	Female	24	38.1
3	Marital status		
	Single	7	11.1
	Married	56	88.9
4	Residential status		
	Rural	18	28.6
	Urban	45	71.4
5	Educational status		
	Higher secondary & Lower	31	49.2
	Graduate or higher	32	50.8
6	Occupational status		
	Unemployed	20	31.7
	Employed	43	68.3
7	Family Income		
	≤ Rs. 5000	7	11.1
	>Rs.5,000	56	88.9
8	Type of payment		
	Hospital concession	5	7.9
	Reimbursement from organization	5	7.9
	Self-payment	53	84.1

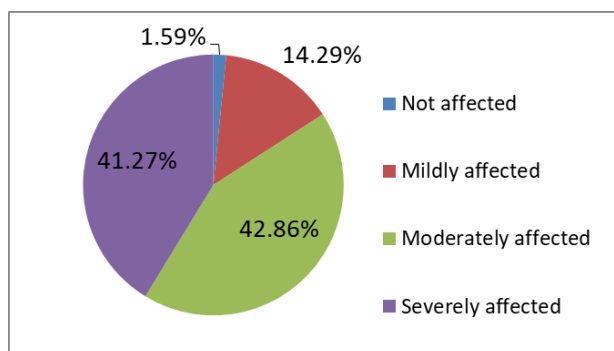
Table 1 shows that majority (55.6%) of the subjects were less than 55 years, males (61.9%) and married (88.9%). Majority (71.4%) of them were from urban areas, holding a degree/diploma in education (50.8%). Most of them were employed (68.3%) and had a monthly family income of more than Rs.10000 (56%). Majority (84.1%) of them paid for medical expenses out of their own pocket. Socio demographic variables were classified into categories for convenience of interpretation.

**Table 2** Distribution of subjects based on their clinical variables (N=63)

S. no	Clinical variable	Frequency	Percentage (%)
1.	Peritonitis Episodes		
	Nil	39	61.90
	1-3	20	31.74
	> 3	4	6.36
2.	Number of Anti-hypertensive drugs		
	1	23	36.5
	2 or more	40	63.5
3.	Duration of CAPD		
	3 months – 1 year	21	33.3
	Above 1 year	42	66.7
4.	Co-morbidities		
	Diabetes	2	3.17
	Hypertension	27	42.86
	Diabetes & Hypertension	14	22.22
	Others*	4	6.35
	Nil	16	25.40
5.	Serum albumin		
	<4 gm%	55	87.3
	4.1 – 6 gm%	8	12.7

\*Chronic pyelonephritis, Glomerulonephritis, Multiple myeloma

Table 2 illustrates that the main cause of the disease is hypertension (42.86%). Some (22.22%) of the subjects had other causes for disease. Majority of them were on CAPD for more than one year (66.7%). Majority had a serum albumin level of < 4 gm% in the last three months (87.3%). Majority of them (61.90%) did not have a prior episode of peritonitis. Clinical variables were classified into categories for the convenience of interpretation.



**Figure 2** Distribution of subjects in relation to illness perception (N= 63)

Figure 2 projects that a majority of patients were moderately (42.86%) and severely (41.27%) affected. This shows a higher percentage of patients perceive illness as a threat.

**Table 3** Distribution of subjects in relation to self-esteem (N=63)

Self-esteem Scores	Minimum score	Maximum score	Mean	%	Standard deviation
Performance Self-esteem	15	34	26.03	74.37	4.432
Social Self-esteem	13	34	25.79	73.68	4.786
Appearance Self-esteem	14	26	19.67	65.56	2.995
State Self-esteem	46	89	71.49	71.49	9.405

Table 3 illustrates the subject's minimum and maximum score of the state self-esteem with their three main domains. The study subjects have scored almost equally in the performance (74.37%) and social self-esteem (73.68%) domains but scored less in the Appearance self-esteem (65.56%) domain.

**Table 4** Distribution of subjects according to their level of self-care management (N=63)

S.N	Self-care management	Percentile	%
1.	Inadequate	0 – 40	0%
2.	Moderately adequate	41 – 80	0%
3.	Adequate	80 – 120	100%

Table 4 shows that all 63 subjects (100%) had adequate self-care management

**Table 5** Relationship between Illness Perception, Self-esteem & Self-care management (N=63)

S.N	Variables	r value	p value
1.	Illness perception Vs Self esteem	- 0.248	0.05*
2.	Illness perception Vs Self-care management	- 0.117	0.363
3.	Self-esteem Vs Self-care management	0.203	0.111

\*p value = 0.05

Table 5 shows that there is a negative correlation between the illness perception and self-esteem which is close to statistical significance ( $p = 0.05$ ). This explains that, more the perceived threat of illness, lower the self-esteem. However, there is no significant relationship between illness perception and self-care management and between self-esteem and self-care management.

**Table 6** Relationship between the duration of illness (illness perception) and self-care management (N=63)

S. N	Variables	r value	p value
1.	Duration of illness Vs Self-care management	-0.290	0.021*

\* $p < 0.05$

Table 6 illustrates that there is a negative correlation between the duration of illness and self-care management. This explains that more the perceived duration of illness, poor the self-care management.

**Table 7** Relationship between the domains of self-esteem and illness perception (N=63)

S. N	Variables	r value	p value
1.	Appearance Self-esteem Vs Effect on life	-0.223	0.079
2.	Appearance Self-esteem Vs Beliefs about effectiveness of treatment	0.377	0.002*
3.	Appearance Self-esteem Vs Degree of understanding of illness	0.239	0.059**
4.	Appearance Self-esteem Vs Emotional aspects	-0.241	0.057**
5.	Performance Self-Esteem Vs Experience of symptoms	-0.316	0.012*
6.	Performance Self-Esteem Vs Emotional aspects	-0.263	0.037*
7.	Social Self-esteem Vs Effect on life	-0.277	0.028*
8.	Social Self-esteem Vs Experience of symptoms	-0.235	0.063
9.	Social Self-esteem Vs Emotional aspects	-0.340	0.006*

\*p &lt; 0.05 \*\*p = 0.05

Table 7 illustrates that there is positive correlation ( $p < 0.05$ ) between appearance self-esteem and belief about the effectiveness of treatment, degree of understanding of illness, and emotional aspects of illness. However, correlation between appearance self-esteem and degree of understanding of illness and its emotional aspects is close to statistical significance ( $p = 0.05$ ).

There is a negative correlation between performance self-esteem, experience of symptoms and emotional aspects which is statistically significant ( $p < 0.05$ ). The table also shows that there is a negative correlation between social self-esteem, effect on life and emotional aspects with statistical significance ( $p < 0.05$ ).

**Table 8** Association of the subject's illness perception with selected socio demographic and clinical variables (N=63)

Variables		Moderately & Severely Affected		Mildly Affected		P Value	Odds Ratio	95% CI of OR
		No.	%	No.	%			
Age	> 55	26	96.3	1	3.7	0.065	7.704	0.90 – 65.96
	≤ 55	27	77.1	8	22.9			
Education	Higher secondary & less	27	87.1	4	12.9	1.0	1.29	0.31 – 5.37
	Diploma & high	26	83.9	5	16.1			
Income	No	2	50	2	50	0.097	0.137	0.17 – 1.13
	Yes	51	87.9	7	12.1			
Duration of CAPD	> 1 year	38	92.7	3	7.3	0.051	5.067	1.12 – 22.91
	≤ 1 year	15	71.4	6	28.6			
Peritonitis episode	1 or more	20	87	3	13	1.0	1.21	0.27 – 5.39
	Nil	33	84.6	6	15.4			
Anti-hypertensive drugs	2 or more	34	85	6	15	1.0	0.89	0.20 – 3.99
	<2	19	86.4	3	13.6			

Table 8 illustrates the association between illness perception with the selected demographic variables like age, education, income and clinical variables like the duration of CAPD, peritonitis episodes and antihypertensive drugs. Patients aged above 55years perceive more illness threat (96.3 %) when compared to those aged below 55years.

Greater the duration of CAPD (>1 year), more the perceived illness threat (92.7%). Patients with prior peritonitis episodes (87%) perceive illness as threat when compared to the patients with no episodes.

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## 4. Discussion

The study was conducted with the core purpose of assessing the illness perception, self-esteem, self-care management and their association with socio-demographic and clinical variables of patients on CAPD. The study was descriptive in nature. A total of 63 subjects participated. The study subjects were selected using total enumeration sampling technique. The results were analyzed using descriptive and inferential statistics.

### 4.1. Description of socio-demographic and clinical variables

The socio-demographic variables of the subjects were age, gender, marital status, occupation status, education status, family income, payment status and monthly expenditure of CAPD. The clinical variables were duration of CAPD, number of peritonitis episodes, and the number of antihypertensive drugs, serum albumin and co-morbidities.

The researcher found that most of the subjects were male (61.9%) and 38.1% were female. Majority of the subjects were less than 55 years (55.6%) of age. Higher percentage of the subjects (63.5%) were on CAPD for more than a year and 33% were on CAPD less than a year, but not less than three months. Most of the subjects (61.9%) did not experience any peritonitis episode whereas 6.36% had more than three episodes and 31.14% experienced less than three episodes of peritonitis. Owing to this finding, it is evident that most of the subjects have taken adequate measures to prevent the complications of CAPD.

The researcher also found that the most prevalent co-morbidity the subjects had is hypertension (42.86%), however, 22.22% had both diabetes and hypertension. Majority of the subjects (55%) had serum albumin less than 4gm% but 12.7% had serum albumin within the range of 4 - 6gm%. This suggested that the participants of the study were compliant with the dietary regimen prescribed. Conversely, most of them (63.5%) were on more than two antihypertensive drugs. This indicates poor fluid and dietary salt compliance. Consequently, it is vital to stress on the importance of fluid and salt restriction while educating these patients.

### 4.2. The first objective of the study was to assess the illness perception, self-esteem and self-care management of patients on continuous ambulatory peritoneal dialysis

Findings of this study on the illness perception revealed that most of the subjects were moderately (42.86%) and severely (41.27%) affected, nevertheless, 14.29% were not affected and 15.9% were only mildly affected. Therefore, this signifies that, most of the subjects perceived illness as a threat to their lives and daily living. A systematic review of five prospective observational studies on illness perception and its association with mortality of dialysis patients concluded that a negative illness perception is associated with increased risk of mortality. They also added that changing negative perceptions with an appropriate intervention can bring about positive outcomes (21). Hence, it is the responsibility of the healthcare team members to consider the patient's attitude towards illness to improve their life expectancy.

The overall mean score of the state self-esteem was 71.49, which indicated a higher self-esteem. The state self-esteem questionnaire consisted of three different components or domains namely performance self-esteem, social self-esteem and appearance self-esteem. The mean scores of performance self-esteem, social self-esteem and appearance self-esteem were 26.03, 25.79 and 19.67 respectively. Interestingly, it was evident that the subjects had lower appearance self-esteem when compared to the other components. This body image disturbance might be due to the nature of chronic illness or the presence of a PD catheter in the abdomen. Moreover, there are no remarkable studies explaining about the body image disturbances in patients on CAPD.

The current study also enlightened the fact that all the study subjects had adequate self-care management. The self-care management questionnaire had five different domains such as peritoneal dialysis technique, catheter site care, trouble shooting, dietary management and the management of complications. Most of the subjects scored high in peritoneal dialysis technique, catheter site care, trouble shooting and management of complications. This explains the reason for a lower incidence of peritonitis. However, scores were comparatively lower for dietary management. This probably explains why 63.5% of the subjects were on more than two antihypertensive drugs. Overall, it is obvious that they follow adequate self-care measures; and the education and training given to them by health care professionals appears to be effective.

#### **4.3. The second objective of the study was to determine the relationship between the illness perception, self-esteem and self-care management of patients on CAPD**

The analysis of the relationship between illness perception and self-esteem reported that there was a negative correlation ( $r = -0.248$ ) which has close to statistical significance ( $p = 0.05$ ). Therefore, this indicates that, higher the perceived threat of illness, lower the self-esteem. A similar finding was observed in a Danish cross-sectional study, where they reported that the patient's belief about their illness had a direct impact on their self-esteem (20).

The researcher also found that there was a positive correlation between appearance self-esteem and beliefs about effectiveness of treatment ( $r = 0.377$ ), and the degree of understanding of illness ( $r = 0.239$ ) with  $p$  values 0.002 and 0.059 respectively. This finding revealed that believing in the effectiveness of treatment and having a good degree of understanding of illness could possibly improve the perception of their body image. Nonetheless, there was a negative correlation ( $r = -0.241$ ) between appearance self-esteem and emotional aspects with a  $p$  value 0.057, which is close to statistical significance. This indicates that negative emotions like anger, fear, depression etc., can affect the appearance self-esteem, for instance, intense remorse or depressive mood could possibly lower the appearance self-esteem.

In the current study, the findings revealed that there was a negative correlation between performance self-esteem and experience of symptoms ( $r = -0.316$ ) and emotional aspects ( $r = -0.263$ ) with  $p$  value 0.012 and 0.037 respectively. It is evident that the performance self-esteem decreases when the patient experiences more symptoms and if the patient is overloaded with negative emotions. Another interesting finding was that the social self-esteem had negative correlation ( $r = -0.277$ ) with effect on life and the emotional aspects ( $r = -0.340$ ) with statistical significance ( $p = 0.028$ ,  $p = 0.006$  respectively). The above finding showed that having negative perception of illness and its effect on life could affect the social life of these patients. Moreover emotional aspects could also pull down social self-esteem resulting in poor socialization or social isolation. In the future, more studies can be carried out with a larger sample size to support these findings. Therefore, the hypothesis stating relationship between illness perception and self-esteem is accepted.

The analysis of the relationship between the illness perception (duration of illness) and self-care management showed that there was a negative correlation ( $r = -0.290$ ) with statistical significance ( $p = 0.021$ ). This highlights that the patient's belief about the duration of illness can affect their self-care management i.e., if the patient believes that the duration of the illness is going to be life-long or incurable, it can probably cause them to lose interest in self-care management as they tend to give up easily. Therefore, the hypothesis stating the relationship between illness perception and self-care management is accepted.

#### **4.4. The third objective was to determine the association between the illness perception and selected socio-demographic and clinical variables**

The chi-square test was used to analyze the association between the illness perception and selected demographic variables like age, education and income. There were no significant findings. However, the chi-square association between the illness perception and selected clinical variable like the duration of CAPD was close to statistical significance ( $p = 0.051$ ). Nevertheless, there was no significant association between the other clinical variables like peritonitis episode and antihypertensive drugs. Majority (92.7%) of those who were affected were on CAPD for more than a year. This reveals that as the duration of treatment increases, the illness is perceived as more of a threat. Therefore, the hypothesis stating association between illness perception and socio-demographic variable and clinical variables cannot be supported.

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## **5. Conclusion**

The current study findings emphasize the need for appropriate nursing interventions to modify their illness perception positively, and to improve their appearance self-esteem.

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## **Compliance with ethical standards**

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### *Disclosure of conflict of interest*

The authors declare no conflicts of interest.



### *Statement of ethical approval*

This study was conducted after approval by the College of Nursing Research and Ethical Clearance Committee on 31<sup>st</sup> July 2019.

### *Statement of informed consent*

Informed consent was obtained from all individual participants included in the study.

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