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Assessment of Illness Perception in End Stage Renal Disease Patients on Hemodialysis in Public Sector Tertiary Care Hospital, Mardan: A Cross-Sectional Study

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Abstract

Background: Chronic kidney disease, specifically end-stage renal disease (ESRD), is a global health burden that demands renal replacement therapy, including dialysis for patient care. ESRD is a noteworthy global health concern, affecting about 14.5% of the world's population. ESRD patients present with physical, emotional and social problems related to their chronic disease. Understanding patients' perceptions of their illness is crucial for improving adherence to treatment plans and overall disease management.

Objectives: The primary purpose of this study is to evaluate illness perception and the relationship between these perceptions and the quality of life of patients with ESRD undergoing hemodialysis.

Methodology: A descriptive cross-sectional study design was employed to compare the illness perceptions of end-stage renal disease (ESRD) patients undergoing hemodialysis at Mardan Medical Complex, a public-sector tertiary care hospital in Mardan, Pakistan. A convenience sampling method was used to select a total sample size of 111 patients, who reported their experiences regarding the perception of illness severity, effectiveness of treatment, and emotional state related to the disease. Before Data collection, Formal permission and approval were obtained from the Ethical Review Board of the relevant department.

Results: Patients identified hypertension as the primary perceived cause of illness in 40.5% of the cases, followed by diabetes mellitus (27%). Regarding the illness, certainty, and concerns, the majority of participants (58.5%) expressed extreme concern. In their perception of illness, participants indicated that they experienced different levels of illness impairment on the emotional aspects (49.6%) were feeling severely affected. Similarly, (45%) perceived that their treatment was moderately effective.

Conclusion: The study emphasizes the need to consider patients' perceptions and attitudes to the disease in treating ESRD. Healthcare workers must ensure that patient education, support activities, and management of emotional complaints are key aspects of improving treatment outcomes and quality of life. The present study suggests the need for additional studies to identify the needs of ESRD patients while on hemodialysis, as well as to conduct interventional studies to enhance their needs being met.

Keywords: End-stage renal disease (ESRD), Hemodialysis, Illness perception, Public sector tertiary care hospital.

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Introduction

Background

Chronic kidney disease CKD is defined as the steady decrease of kidney function over time. Chronic kidney disease (CKD) can reach the most severe state, called end-stage renal disease (ESRD), at which point the kidneys' function is permanently impaired. ESRD is a condition with a multifactorial concept, and common causes include glomerulonephritis, diabetes mellitus and hypertension.[1] The burden of CKD and ESRD is growing in Pakistan, associated with high occurrence of risk factors like diabetes, hypertension and infectious diseases [2].

ESRD has become a significant public health problem from a global perspective and could pose a substantial healthcare burden. ESRD patients rely on renal replacement therapy, including hemodialysis, for fluid and electrolyte management, as well as the removal of waste products from the body (3). ESRD, in particular, has become a significant burden in Pakistan; its incidence is on the rise, but the facilities to manage ESRD, especially in public sector tertiary care hospitals, are scarce. This drastically increased incidence rate affecting not only developing countries but also developed countries has also increased in prevalence due to a more ageing population and lifestyle-related comorbidities like hypertension and diabetes mellitus. This increased prevalence is directly linked with increased mortality and increased morbidity rate [4]

Hemodialysis is a process that filters waste products and fluid from a patient's blood using a dialysis machine. However, hemodialysis is a therapy that poses a considerable burden on patients in terms of physical and psychosocial aspects of their lives, such as diet, drugs, and the psychic states [2]. This study focuses on analysing illness perceptions about their condition and therapy to improve the quality of care. [5]. Severe medical disorders such as end-stage renal disease (ESRD) and chronic kidney disease (CKD) have recently become global health issues, including in Pakistan [6].

The main problems associated with these illnesses are their treatment costs, which can lead to severe financial hardships, particularly in a nation like Pakistan, where the majority of people cannot afford these costly therapies. These elements could therefore lead to a considerable rise in the morbidity rate and mortality of ESRD [7],[8].

Dialysis patients received the lowest quality of life scores in a Chow and Wong study in terms of their physical health, social function, and CKD features, such as job status and illness load. [9]. The majority of dialysis patients experience job loss or income reduction, which lowers their standard of living, causes financial difficulties, and alters their quality of life [10].

Understanding the illness perception among ESRD patients on hemodialysis is paramount for healthcare providers in delivering patient-centred care and addressing the multifaceted needs of this population. Illness perception may be defined as the knowledge that patients have about the disease, including their perceived understanding of the ailment's cause, prognosis, time frame, level of personal control, and even their feelings about the disease. These perceptions play a key role in how the patients manage their illness, what behaviours relate to self-management, and how fully they stick with their treatment regimens [11]

Rationale for the Study

As the number of patients with ESRD increases and the need for hemodialysis continuously rises in Pakistan, limited literature focuses on the illness perceptions of patients. Research conducted in other countries also shows that patients' perceived illness beliefs affect their treatment compliance, health-related behaviours, and quality of life [12]. Hence, exploring illness perception among ESRD patients on HD in Pakistan, specifically in Mardan, will allow us to identify key factors influencing the patients' experience and help in designing appropriate strategies to enhance their care.

Objectives

The primary objective of this research is to evaluate illness perception among ESRD patients undergoing hemodialysis in a public sector tertiary care hospital in Mardan. The specific objectives of the study are: Firstly, to investigate how patients undergoing hemodialysis (HD) perceive their illness, and secondly, to evaluate the relationship between these insights and the patients' quality of life.

Significance of the Study

The results of this study will have practical implications for instant clinical advancements, policy making, and future research directions in the fields of nephrology and public health. In addition, the study could help enhance knowledge regarding the management of ESRD in developing countries, including Pakistan, in terms of identifying attributes and policies that can be used in organising essentials and extending treatment for ESRD patients.

Research Questions

The research questions guiding this study are:

- What are the illness perceptions of ESRD patients undergoing hemodialysis?

- How are these perceptions manifested, and what is the effect of these perceptions on patient outcomes and quality of life?

Prevalence of End-stage renal Disease:

Around the world, 9% of people have End Stage Renal Disease (ESRD), and 2.5 million of them receive treatment for renal failure each year. The awareness of this significant burden is relatively recent and still incomplete. Chronic kidney disease (CKD) is becoming a serious global public health concern; reports indicate that South Asian populations have a greater incidence of CKD than European populations. Because there isn't a national registry in Pakistan to gather information on dialysis patients, the prevalence of CKD is rising. [13]. The high rates of diabetes and hypertension, a deprived primary health care system, the low level of health education, and the inadequate government assistance are thought to be the causes of Pakistan's high incidence of chronic kidney disease (CKD) [14]. Meanwhile, estimations indicate that in Pakistan, 150 individuals out of every million people have end-stage renal disease (ESRD) yearly [15]. Since Pakistan is a developing nation, nephrology-related services and treatments are still being established. The annual cost of dialysis treatment for each patient is approximately \$3,000 [16].

Chronic kidney disease (CKD) is becoming a serious global public health concern; reports indicate that South Asian populations have a greater incidence of CKD than European populations, because there is a national registry in Pakistan to gather information on dialysis patients. The prevalence of CKD is rising [17].

According to a recent review, Pakistan had the most significant prevalence (23.3%) of end-stage renal disease (ESRD) among participants among four South Asian nations, while Nepal had the lowest (10.6%) prevalence [18]. According to one study conducted in the Pakistani Peshawar area, patients with diabetes had an 11-fold higher prevalence of ESRD, and non-hypertensive individuals had a 7.29-fold lower prevalence [19]. Even so, it is still unclear how many people in Pakistan have end-stage renal disease (ESRD); research has suggested that the incidence rate is 152 per million [20].

According to a 2018 study conducted by the Pakistan Medical Association, Pakistan, being a developing nation, has a high number of patients suffering from kidney disorders. Twenty million patients have kidney disease, and 20,000 people pass away from it annually. Based on data from 2008, approximately 6,000 individuals are undergoing dialysis treatment; this indicates that only about 40% of patients in the nation are using dialysis services [21].

Illness Perception in Hemodialysis Patients

The illness perception, which is the impression of sickness among patients undergoing hemodialysis, encompasses their beliefs about their condition, the reasons for it, its effects, and their perceived ability to manage it [22]. Dialysis patients received the lowest quality of life scores in a study by Chow and Wong in terms of social function, physical health, and CKD aspects such as job status and illness load [23]. Patients with chronic kidney disease (CKD) exhibit higher levels of anxiety and depression in relation to their clinical diagnosis. Furthermore, anxiety and depression levels rise in respect to the severity of chronic kidney disease [24].

According to the Self-Regulation Model [25], patients' perceptions of their illness are a component of a self-regulatory framework that helps them make sense of their condition and choose coping mechanisms and health-related behaviours, such as using medication or visiting the clinic, in an effort to manage the threat of their illness. An individual's experience with ESRD affects every part of their life. ESRD is a chronic, debilitating illness that impairs a person's emotional and social interactions, moreover to their physical and psychological health [26].

Eventually, the chronic nature of this illness may have an impact on the patient's psychological well-being, leading to social isolation, worry, stress, and depression that worsen their quality of life [27]. Their physical condition also exacerbates the disease. They must adhere to a strict diet, limit their fluid intake, schedule regular dialysis visits, and manage their spare time and leisure activities [28]. Both cognitive and emotional factors contribute to its influence, including the disease's predicted course, the effects it will have on one's life, how it is managed or treated, the identification and source of the illness, and feelings such as dread or worry about it [29].

Gap Analysis Related to Illness Perception

Due to the high incidence of kidney diseases and rising treatment costs, it has garnered international attention. Based on approximate data, prevalence rates of 10.2% to 13% have been reported globally [30]. It has also been noted that people from lower socioeconomic classes may experience greater suffering as a result of renal illness going undiagnosed and untreated, particularly in low- and middle-income nations [31]. In these situations, several factors have been linked to the patients, including inadequate encouragement of physical activity, healthy eating, and access to healthcare information, all of which impact a person's quality of life [32].

Assessing the degree of adherence in HD patients enables the implementation of measures that aim to minimise the harmful effects on well-being and overall cost, primarily for healthcare consumers who are non-adherent [33]. When patients under hemodialysis fail to adhere to medical instructions, the mortality and morbidity, as well as the cost of treatment, increase. A previous study has established a positive relationship between hopelessness and the feeling of sickness amongst patients with HD [34,35]. Stress or anxiety affects everyone who believes that their illness

is fatal. This study found that they had assumed that their understanding of psychosomatic illness, the need for social support, and the level of urea, before dialysis in ESRD patients [36]. Qualitative surveys can provide valuable insights into the theoretical understanding of End-Stage Renal Disease (ESRD) by integrating patient experiences [37].

Methodology

Study design

A descriptive cross-sectional study design and a convenience sampling technique were employed to evaluate illness perception in patients with end-stage renal disease undergoing hemodialysis. The study was conducted at Mardan Medical Complex and Teaching Hospital, a well-established tertiary care hospital in Mardan. Before Data collection, Formal permission and approval were obtained from the Ethical Review Board of the relevant department.

Sample size

The sample size for the study was calculated using online Epi software with a 95% confidence interval and a 5% margin of error. The population size (N) was determined to be 155, with a hypothesised frequency of the outcome factor (p) set at 50% +/- 5. The confidence limits (d) were specified as 5%. The formula used for the calculation is as follows:

$$\text{Sample size } n = [\text{DEFF} \cdot Np(1-p)] / [(d^2 / Z^2 \cdot 1 - \alpha / 2 \cdot (N-1) + p \cdot (1-p))]$$

The results from the calculation, based on a 95% confidence level, indicate a sample size (n) of 111 was found.

Participants

All patients aged more than 15 years who presented to the dialysis unit, were willing to participate, and had a confirmed diagnosis of CKD within the past 6 months were included in the study. The Exclusion Criteria were Patients aged below 15 years, those not eager to participate in the study, and those who had been diagnosed with CKD for less than 6 months.

Data tool

The study tool consisted of sections; Section A contained demographic details. Section B contained Illness Perception questions. The Brief Illness Perception Questionnaire comprises nine items; the first five items evaluate cognitive perceptions related to the illness: (Item 1): Measures the impact of the illness on one's life. (Item 2): Assesses the perceived duration of the illness. (Item 3): Examines the individual's perception of control over the illness. (Item 4): Investigates beliefs regarding the effectiveness of treatment. (Item 5): Explores the experience of symptoms associated with the illness. (Items 6 and 8): Evaluates emotional aspects and the degree to which the illness affects emotions. (Item 7): Measures the level of understanding the individual has about their illness. The final item is an open-ended Question, prompting respondents to list the top three factors they believe are causing their illness. It's essential to note that the tool is administered in both English and Urdu for the participants' understanding. The researcher also explained the questionnaire in the Pashto language to illiterate patients.

Data Analysis and Statistical Approaches

The statistical analysis of the data was conducted precisely to ensure a comprehensive understanding of illness perception in patients with end-stage renal disease. The data were entered into SPSS version 22 and subjected to descriptive statistics. Categorical values such as gender, socioeconomic status, and marital status were presented using frequency and percentage tables.

Ethical consideration

In this study, ethical consent was obtained from the Ethical Review Committee of Khyber Medical University, Peshawar. Furthermore, consent was sought from the Medical Director of Mardan Medical Complex to obtain information about patients. As a prerogative for data collection, every study participant provided a written informed consent. Participants' informed consent contained information about study aims, possible harms, advantages and participants' right to withdraw from the study.

Results

Table 1. Demographic Data

Demographic Variables		N	%
Age group	15-30	65	58.6%
	31-40	46	41.4%
Gender	Male	62	55.8%
	Female	49	44.2%

Educational Background	Uneducated	47	42.3%
	Primary school	38	34.2%
	Matriculation	22	19.8%
	Intermediate	3	2.7%
	Bachelor	1	0.9%
Marital status	Single	19	18%
	Married	92	82%
Monthly income	Less than 20000	31	27.9%
	From 20000 to 40000	52	46.8%
	Above 40000	28	25.3%
Occupation	Gov. employer	2	1.8%
	Labor	17	15.3%
	Shop keeper	15	13.5%
	Farmer	9	8.1%
	Housewife	42	37.8%
	Business	9	8.1%
	Jobless	17	15.3%

The study included a total of 111 participants. In this study, the majority of the participants were male, n=62 (55.8%), followed by female, n=49 (44.2%). Almost 58.6% (n=65) of the study participants were in the 15-30 year age group, and 41.4% (n=46) were aged 30 years or older. With regard to educational background, most participants, n=47 (42.3%), were Uneducated, followed by those with a Primary school education, n=38 (34.2%), and Matriculation, n=22 (19.8%). Of the 92 participants (82%), 82 were married, and 19 were single (18%). The Monthly income of the majority of participants, n = 52 (46.8%), was between 20,000 and 40,000, followed by n = 31 (27.9%) who had less than 20,000.

Table 2. Brief Illness Perception-related questions

S.NO	Brief Illness perception related questions:	None N (%)	Mild N (%)	Moderate N (%)	Severe N (%)
1	How much your illness affects your life?	4 (3.6%)	16 (14.4%)	16 (14.4%)	75 (67.6%)
2	How much control do you feel you have over your illness?	11 (9.9%)	20 (18%)	25 (22.5%)	55 (49.6%)
3	How much do you experience symptoms from your illness?	7 (6.3%)	29 (26.2%)	30 (27%)	45 (40.5%)
4	How well do you feel you understand your illness?	16 (14.4%)	20 (18%)	49 (44.1%)	26 (23.5%)
6	How much do you think your treatment can help your illness?	5 (4.5%)	21 (19%)	35 (31.5%)	50 (45%)
7	How much does your illness affect you emotionally? (E.g. does it make you angry, scared,	2 (1.8%)	19 (17.1%)	35 (31.5%)	55 (49.6%)

	upset or depressed?				
8	How concerned are you about your illness?	7 (6.3%)	13 (11.8%)	26 (23.4%)	65 (58.5%)

Table 2 demonstrates the Brief Illness Perception-related questions. The Illness Perception Questionnaire was administered to 111 participants to assess their perceptions of their illness. The survey measured responses on a scale from "none" to "severe." Out of 111 participants, 75 (67.6%) reported that their illness had a severe impact on their life, followed by 16 (14.4%) who reported a moderate or mild impact on their life. Of the 55 participants (49.6%), 55 stated that they severely lack control over their illness, followed by 25 (22.5%) who have moderate control and 20 (18%) who have mild control over their illness.

The majority of them, $n = 45$ (40.5%), Experienced severe symptoms related to ESRD. Most responders, $n = 49$ (44.1%), reported having a moderate understanding of their illness. $n=16$ (14.4%) reported having no understanding, who need further education about their illness. $n=50$ (45%) of participants believe that their treatment would have a positive impact on their illness and can improve their condition. In this study, $n=55$ (49.6%) of participants were suffering from severe emotional distress due to their disease condition. Of the 65 contributors (58.5%), 65 were severely concerned about their illness. These results suggest that the contestants generally report a high level of impact, emotional distress, and concern about their illness, but a low level of control and understanding.

The most important factors that patients believe caused their illness are listed in Table 3.

Table 3. Essential factors that caused the Patient's illness

Causes	N (%)
Hypertension	45 (40.5%)
Diabetes mellitus	30 (27%)
Kidney stone	20 (18%)
Prostate	04 (3.6%)
Trauma	12 (10.9%)

Most important factors that patients believe caused their illness are Hypertension $n=45$ (40.5%), Diabetes mellitus $n=30$ (27%), Kidney stone $n=20$ (18%), Trauma $n=12$ (10.9%) and Prostate $n=4$ (3.6%).

Discussion

According to our survey, the majority of ESRD patients believed that their illness had a significant impact on their lives, experienced mild to moderate symptoms in their day-to-day activities, and reported understanding their condition. ESRD patients think that DM and HTN are the primary causes of their health issues, such as ESRD; the illness has a significant emotional impact on the patients, and they are pretty worried about their condition. Upon assessment of illness perception among End-Stage Renal Disease (ESRD) patients undergoing hemodialysis at a public sector tertiary care hospital in Mardan, the findings revealed a perception of severe illness significantly affecting patients emotionally. Hypertension emerged as the primary perceived cause of illness for 40.5% of patients, followed by diabetes mellitus (27%) and kidney stones (18%). These findings align with previous studies identifying hypertension and diabetes mellitus as predominant contributors to ESRD. This perception of treatment ineffectiveness may stem from various factors, including medication non-adherence, insufficient disease education, and limited access to healthcare resources [38]. Patients receiving hemodialysis report better treatment adherence due to treatments that promote disease awareness. Patients will adhere more closely to their treatment plans if they feel more positive about their health [39].

Moreover, a significant percentage (49.6%) of the patients claimed that they felt emotionally painful as patients with other forms of the illnesses. This shows the significance of how the mental consequences of ESRD should be managed by medical care and specific psychological courses provided. The studies also reveal that some interventions, comprising mindfulness-based stress reduction and cognitive behaviour therapy (CBT), are helpful in enhancing the state of self of patients with ESRD [40]. The study also revealed that a large number of patients (58.5%) showed severe concern about the illness. The findings align with those of Santos-Araújo et al. (2023) [41], who reported that demographic variables such as age, gender, and socioeconomic status. Furthermore, Wang et al. (2023) found similar patterns in the Chinese population, where younger patients reported lower perceptions

compared to older individuals, suggesting that age is a consistent predictor across populations [42].

The work of Muscat et al further supports the current study.[43], who indicated that illness perception significantly impacts mental health outcomes among CKD patients. They reported that patients with negative perceptions of their illness were more likely to experience psychological distress, such as depression, which is consistent with the present study's observation of varying perception levels. Additionally, Suganthi et al. (2020) identified a direct link between illness perception and treatment adherence among patients with end-stage renal disease [44]. Their study showed that patients with a low perception of their condition had poorer treatment adherence, correlating with our findings, where (40.5%) of participants exhibited a low illness perception, which could indicate potential issues with treatment compliance in this subgroup [45].

The two aspects of illness perceptions that are thought to be significant are either the manageability of CKD or the seriousness of CKD. It's interesting to notice that patient and expert responses frequently overlapped, indicating that these professionals had sufficient understanding of patients' perceptions of CKD. A study found a correlation between HD patients' poor survival and their perceptions of disease [46]. Our findings add to earlier research that showed how illness perceptions affect survival in this patient population, regardless of age, comorbidity, or depression symptoms [47].

Conclusion

Assessing illness perception in end-stage renal disease patients undergoing hemodialysis is crucial for delivering adequate healthcare and management. The way end-stage renal disease patients perceive their illness has a significant impact on their emotional well-being, adherence to treatment, and overall quality of life. Regarding such views, several factors influence social support, cultural issues, coping styles, and illness perceptions. Thus, it is possible to empower patients, increase flexibility, and improve health outcomes when it comes to the delivery of psychological support, education, and effective communication between patients and their healthcare professionals.

Therefore, to enhance outcomes in this group of patients, there is a need for a comprehensive model that emphasises patient-centred treatment, psychological and emotional support, as well as a supportive environment.

Implication of the study

The findings of this study show that understanding illness perceptions and concerns that patients have about their illness is essential if they are to receive adequate psychological and medical support that enhances their health. In addition, the study also emphasises the fact that patients' physical aspects are not the only things that need to be considered by the healthcare providers; there are also the psychological aspects of patients. ESRD is associated with a high rank of psychological distress; these factors have an impact on the patients and the completion of the intended treatments.

The limitation of the present study is that it was conducted in a single tertiary care hospital in Mardan city, Pakistan. Therefore, the extent to which these findings can be generalised to other settings is likely to be limited. Since it was a cross-sectional study, the association between illness perception and emotional distress remains inconclusive.

The current study's strength lies in its localised focus, allowing for specific insights into the socio-cultural factors influencing CKD patients in Mardan, Pakistan, but further studies are needed to confirm these observations across varied populations. Future research should thus seek to overcome these limitations by using a greater sample size and multiple research settings, so that the conclusion can be generalised. Furthermore, future studies may examine the roles of other interventions for patients with ESRD, including psychological distress and illness perception. Moreover, future research could focus on testing the impact of patients' illness perceptions and concerns as variables on where patients received the intervention, on both psychological and physical health.

Declarations

Data Availability Statement

Data is available upon request due to privacy and confidentiality concerns. The data presented in this study are available on request from the corresponding author. The data are not publicly available due to privacy and confidentiality.

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Institutional Review Board Statement

Researchers obtained ethical approval from the Ethics Committee of the Faculty of Public Health, Khyber Medical

University, Peshawar, Pakistan, with permit number KMU/IPHSS/Ethics/2023/GD/01103.

Informed Consent Statement

Informed consent was obtained from all respondents included in this study, and it was signed voluntarily without coercion.

Conflicts of Interest

The authors declare that there is no conflict of interest regarding the publication of this manuscript.

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