

# REFUSAL OF DIALYSIS AMONGST PATIENTS OF CHRONIC KIDNEY DISEASE (CKD)

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## Abstract

**Objective:** This study was conducted to determine the refusal of dialysis amongst patients of chronic kidney disease presenting for the first time for dialysis in uremic condition.

**Study Design:** Cross sectional Study.

**Place and Duration of the Study:** Outpatient department of Nephrology, Mayo Hospital, Lahore from 1<sup>st</sup> Jan 2012 to 31<sup>st</sup> December 2012.

**Patients and Methods:** Patients of CKD due to any cause presenting with uremia for the first time for dialysis were included in the study. History and physical

Professor of Pathology. Shalamar Medical and Dental College, Shalamr Hospital, Lahore – Pakistan examination was done and demographic data was collected in pre designed form. Patients were offered for dialysis while explaining to them the advantages of getting and disadvantages of not getting dialysis. Patient's response on the offer was recorded and the reason for the refusal were noted.

**Results:** According to the criteria 150 patients were included in the study. Most of the patients were male 92 (61.3%) and illiterate 78 (52.0%). Major cause of CKD was diabetes mellitus 58 (38.7%) followed by hypertension 38 (25.3%). Mean age of the patients was  $42.59 \pm 13.72$  year and income of the most of the patients 126 (84%) was less than US\$100/-month. Most of the patients 126 (77.0%) were asked about the need of dialysis in less than three months, 61 (41.3%) offered for the first time and amongst them 85 (54.0%) were offered dialysis already. Majority of the patients 101 (67.3%) refused dialysis when it was offered to them for the first time. Major reason of the refusal was fear of dialysis procedure in 76 (76%) patients followed by treatment by spiritual 14 (14%) and alternative ways and others 11 (11%). Middle age persons refused dialysis significantly.

**Conclusion:** Diabetes mellitus is the leading cause of CKD. Most of the patients were informed about dialysis at very late stage. Majority of the patients refused dialysis. Major reason of the refusal was fear of dialysis procedure followed by treatment from some spiritual ways and alternative treatment.

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**Key words:** CKD, Hemodialysis, Refusal, Acceptance, Demographic factors.

**Introduction**

Chronic kidney disease (CKD) is defined when kidney functions are impaired over weeks to months and glomerular filtration rate (GFR) is less than 60 ml/min/1.73 m<sup>2</sup>.<sup>(1)</sup> There are five stages of CKD depending on the basis of GFR.<sup>2</sup> According to local research every third person in Pakistan is suffering from kidney disease.<sup>3</sup> The incidence of end-stage renal disease (ESRD) is estimated to be about 150 patients / million population per year in Pakistan.<sup>4</sup> When patient develops ESRD then there are two treatment options like dialysis and renal transplant. Dialysis is of two types i.e. hemodialysis (HD) and peritoneal dialysis (PD). In Pakistan almost all of the patients get HD as experience with PD is very limited and it is more expansive than HD.<sup>5</sup> Nephrology and dialysis services are in the early stage of establishment in Pakistan. Due to preliminary stages of establishment of dialysis services, patient of CKD have lot of reservation about dialysis in their minds. In our population it is commonly observed that patients of ESRD are reluctant in starting dialysis and they refuse it. Acceptance or refusal of dialysis affects not only quality of life of dialysis patients.<sup>6-9</sup> But even mortality. In Pakistan none of the study has been conducted yet which exactly shows that how many patients refuse in getting dialysis and what factors are responsible for it. So this study was conducted to determine the causes of refusal and factors affecting it.

**Patients and Methods**

This cross sectional study was conducted in outpatient department of Nephrology of Mayo Hospital, Lahore from 1<sup>st</sup> Jan 2012 to 31<sup>st</sup> December 2012. Patients of CKD due to any cause presenting with uremia for the first time for dialysis were included in the study. Patients of Acute Kidney Injury or who were already on dialysis were excluded from the study. Demographic data was collected on a predesigned Performa containing age, gender, education, income and employment status. Patients were divided into different groups on the basis of age, gender, education level & monthly income. Treatment history including previous treatment, previous advice for dialysis was taken. Blood samples were drawn for performing routine hematological and biochemical profile of the patient. Patients with CKD and uremia were asked for dialysis while explaining to them the advantages of getting and

disadvantages of not getting dialysis. Patient’s response and its causes of refusal were noted. SPSS version 16.0 was used for data analysis. For categorical variable frequencies and percentage were calculated and for continuous variable data was expressed by mean ± SD. Chi-Square test was used to determine the association among categorical variables. P value less than 0.05 was taken as statistical significance.

**Results**

In this study one fifty patients who fulfill the criteria were included in the study. Most of the patients were male 92 (61.3%) and illiterate 78 (52.0%). Major cause of CKD was diabetes mellitus (DM) 58 (38.7%) followed by hypertension (HTN) 38 (25.3%). Mean age of the patients was 42.59 ± 13.72 years and majority of the patients 84 (56%) were in the range of 38 to 60 years. Only 26 (17.3%) patients were employed and rests of the patients were either unemployed or dependent. Most of the patients 126 (84%) income was less than US\$100/month. Laboratory data of the patients is shown in Table 1. Almost all of the patients 143

**Table 1:** Showing Continuous Variables of the patients (n = 150).

Sr. No.	Factor	Mean ± SD
1	Pulse (per min)	83.21 ± 9.42
2	Systolic BP (mmhg)	144.24 ± 28.71
3	Diastolic BP (mmhg)	86.75 ± 15.99
4	Hb (gm/dl)	8.06 ± 1.89
5	Urea (mg/dl)	191.59 ± 67.7
6	Creatinine (mg/dl)	11.129 ± 4.6
7	Albumin (gm/dl)	3.69 ± 0.55
8	Serum Sodium (mmol/l)	134 ± 8.0
9	Serum Potassium (mmol/l)	4.87 ± 0.912
10	Serum Calcium (mg/dl)	7.74 ± 1.80
11	Serum Phosphorus (mg/dl)	4.8 ± 2.48

(95.4%) were anemic. Eighty one (54.0%) patients came to know that they have kidney disease in less than three months and they were getting medical treatment. Most of the patients 126 (77.0%) were informed

about dialysis in less than three month and amongst them 62 (41.3%) patient came to know about the need of dialysis for the first time. Majority of the patients 101 (67.3%) refused dialysis when it was offered to them for the first time as shown in Figure 1. Major reason of the refusal was fear of dialysis procedure in 75 (76%) patients followed by treatment by spiritual and alternative medicines 14 (14%). Other reasons of the refusal were death of relative of CKD patients on HD and non availability of nearby dialysis center 4 (4%) as shown in Figure 2. Some patients were having multiple reasons for the refusal of dialysis. Income, gender and educational level does not affect refusal of dialysis ( $p > 0.05$ ). Age was affecting significantly in refusal of dialysis ( $p = 0.019$ ) and middle age persons refuse dialysis than younger and older age groups.

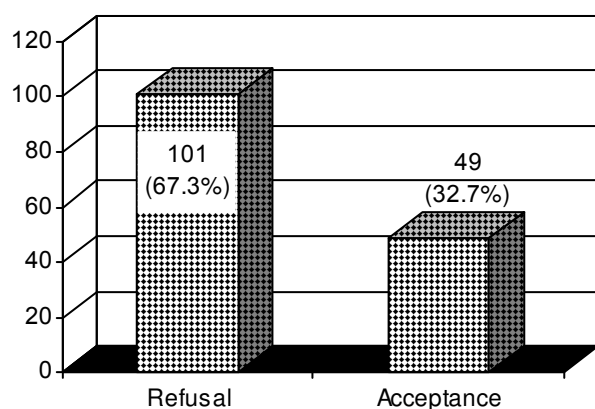


Figure 1: Refusal/Acceptance of dialysis.

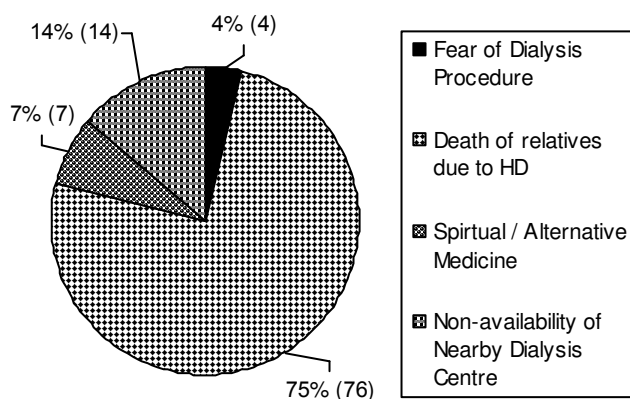


Figure 2: Causes of Refusal of Dialysis.

## Discussion

In this study, diabetes mellitus is the leading cause of CKD which is similar to local studies<sup>10-11</sup> and another study conducted in Indian Subcontinent.<sup>12</sup> Similar pattern of the causes of CKD was observed in developed countries.<sup>13</sup> This pattern of CKD is different from the last decade in which chronic glomerulonephritis was the leading cause of ESRD.<sup>14,15</sup> This change in the pattern of the disease is due to change in the life style and urbanization. Initially the diabetes mellitus was the disease of the developed countries but now it is becoming two to three times more in the Indian subcontinent and is projected to triple over the next two decades. As one third of the patients are going to develop diabetic nephropathy leading to CKD, so there will be drastic increased in the prevalence of diabetic nephropathy in next decade.

In this study, almost all of the patients 143 (95.4%) were anemic which is similar to another local study<sup>16</sup> and study conducted in Nigeria.<sup>17</sup> But it is different from international literature where 45% of the patients are anemic on presentation in CKD stage 5.<sup>18</sup> This severity of the anemia in our patients shows the status of pre dialysis care of the CKD patients before coming to tertiary care centers. Even the status of patients who are getting dialysis is not improving after coming to dialysis centers. According to Anees et al,<sup>19</sup> 86% of the patient were anemic (Hb =  $9.58 \pm 2.30$  gm/dl) who were getting dialysis with mean duration of 13 months. But in United States two third of the patients on HD have Hb level between 11 – 13gm/dl.<sup>20</sup> This is the difference between under developed and developed countries. In underdeveloped countries the focus is still on the survival of the patients as compared to developed countries where the focus is above the survival and more on the quality of life of dialysis patients. In underdeveloped countries the financial constrains is one of the important reasons for this disparity as most of the people live below the poverty line. In Pakistan, dialysis expenses are about US\$ 4000/year whereas per capita income is US\$1368.<sup>21</sup> According to above study,<sup>19</sup> only 46% of the patients were getting EPO in our patients as compared to 90% on maintenance HD in United States.<sup>22</sup> So most of the people cannot meet regular thrice weekly dialysis, along with monthly investigations.

In this study most of the patients were informed that they have kidney disease at very late stage. Similarly majority of the patients 117 (78.0%) were asked about the need of dialysis in less than three months. According to international guidelines patients with CKD should be referred to Nephrologist when GFR is

less than 30 ml/min<sup>23</sup> and 70% patients should start dialysis through AV fistula. In Pakistan health system is very weak and there is no proper referral system from General Practitioners (GPs) to tertiary centers, so patients are referred to nephrologists in very serious condition. Late referral to nephrologists causes high morbidity and mortality of dialysis patients.<sup>24,25</sup> According to local study<sup>10</sup> there is 100% late referral of dialysis patients to nephrologist and not only a single patient was having permanent access for dialysis. In Pakistan, nephrology services are very poor and there are very limited number of Nephrologists. There are about 80 formally trained nephrologists in Pakistan for population of about 160 million as compared to USA where there are more than 5000 nephrologists for a population of 30 million.<sup>3</sup> So patients have no awareness about Kidney disease physicians – Nephrologists. Even the medical professional persons have very limited knowledge about the referral of kidney patients to nephrologists. Due to the shortage of the nephrologists, there are no screening programs for the early detection of the CKD patients amongst general population and population at risk. Along with that these patients are detected at a very late stage when they are already very weak, malnourished and have multi organ involvement. Before coming to nephrologists these patients are not properly counseled about the severity of the disease and its long term management decisions. Shortage of nephrologists not only affect pre ESRD care but even the post dialysis care is not up to the mark because most dialysis centers are being run by technicians and non kidney physicians which makes the situation further grave.

Dialysis is the treatment modality for ESRD patients. In the last decade, there are improvements in dialysis expertise and dying patient not only survives but enjoys a better quality of life with terminal disease. But in Pakistan, people have not accepted it as treatment modality and they think that dialysis means death. In this study most of the patients refused for the dialysis when it was offered to them. Even at that time, patients and their attendants were fully counseled and explained to them the advantage of getting and disadvantages of not getting dialysis. Even then patient attendants were not willing and they took the patient to home. It was observed that these patients present later in very critical condition for dialysis. Most of these patients die either immediately or in couple of months leading to very high mortality of ESRD patients. In this study major cause of the refusal of the dialysis was fear about the dialysis procedure. It is different

from our neighboring country India,<sup>26</sup> in which major reason for not accepting the dialysis was finances and logistic problems. Actually, the reason of this difference is that, in Punjab Province government is providing free dialysis services at the public sector hospitals so financial reasons are not important in this study. In last couple of years there is tremendous improvement at the government level for providing dialysis services close to the patient's residences. For this government has provided dialysis services at the District and Tehsil headquarter hospitals. So this is the reason that logistic problems are not important in the refusal of dialysis. In Pakistan patients of CKD have lot of misconceptions about dialysis. When nephrologists break the news to them they become anxious and seem depressed. Even the quality of dialysis delivered is not up to the mark which leads to poor health related quality of life which further enhances the fear of dialysis amongst the community.<sup>27</sup>

After fear of dialysis procedure other reasons of refusing dialysis was spiritual and alternative treatment and death of the relative of the CKD patients in the past due to dialysis. Some patients believe that there is no treatment for ESRD patients in medicine and they look for some spiritual methods and alternative medicines. This thing leads to reluctance in getting dialysis. In our study most patients 85 (56.7%) were already informed about dialysis at periphery or at other hospitals but patients were looking for some miracle for improving kidney functions and they moved to tertiary care hospitals. In short there are multiple reasons for the refusal of dialysis. In this study refusal of the dialysis was statistically significant in middle age persons than younger and older age persons.

## Conclusion

Diabetes Mellitus and Hypertension are leading causes of CKD. Most of the patients were informed about dialysis for the first time or less than three months on presenting to nephrologist after the development of the disease. Majority of the patients refused dialysis. Major reason of the refusal of the dialysis was fear of the dialysis procedure. The results highlight the need for creating the awareness of the CKD amongst people so that acceptance of the dialysis can be improved and early initiation can take place. There is need to train more and more nephrologist which will create awareness amongst medical persons about CKD. Continue

Medical Education (CME) programmes should be started for the training of GPs.

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