Pakistan Renal Registry

Annual report 2024

Pakistan Society of Nephrology

Renal Registry Data: Annual Report 2024
Pakistan Society of Nephrology (PSN)

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Date of Report	

This registry aims at collecting data from all over Pakistan and accumulation of that collected data on one singular forum accessible to the members of the committee. This data shall be conducted as per the Ethical guidelines under the approval of local ethical bodies. The data is kept confidential, and no personal identifiers are shared. The patient data is used to identify trends and find gaps in recent indications of renal diseases and the outcomes of various treatment options available.

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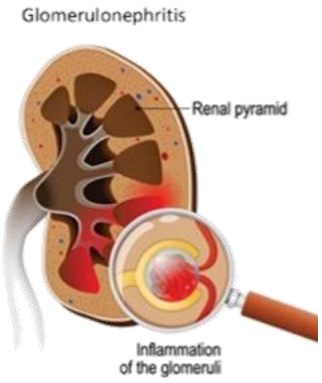
List of Abbreviations

PSN	Pakistan society of nephrology
PSN-RR	Pakistan society of nephrology-Renal Registry
PSNRC	Pakistan Society of Nephrology Research Committee
CRO/SMO	Contract research organization, Site Management organization
PJKD	Pakistan journal of kidney diseases
RCT	Randomized controlled trial
TORs	Terms of Reference
AE	Adverse Event
CRF	Case Report Form
EC	Ethics Committee
EDC	Electronic Data Capture System
FDA	Food and Drug Administration
ICH	International Conference on Harmonization
IFU	Instructions for Use
IRB	Institutional Review Board
HCV	Hepatitis C Virus
PI	Principal Investigator
QRG	Quick Reference Guide.

Background

Pakistan has a growing prevalence burden of patients with kidney diseases, with nearly 17 million people falling victim to chronic kidney disease and ranked 8th in the world for the people affected by kidney diseases.[1] The prevalence of chronic kidney disease is 21% as per a recent review.[2] The patients, who suffer from CKD may experience higher than normal early morbidity in the form of cardiovascular diseases as well as an imminent progression of the disease to End Stage Renal Disease (ESRD).[3] A variety of factors, including but not limited to underlying predisposing medical illnesses, genetic predisposition, environmental factors, sociocultural factors, and other elements, including healthcare systems and access to healthcare, might affect the clinical results for people with chronic kidney disease (CKD).[4]

Glomerular disease is also frequently identified in patients with kidney diseases, over which the primary glomerulonephritis dominates with 77% of the total diseases.[5,6] There has been significant variability in the epidemiology of the etiology of nephrotic syndrome, and some nephropathies are more common in particular age and racial groups. These results might point to a change in the pattern of sickness or a better understanding of glomerular abnormalities.[7] Apart from genetic profile, other possible explanations for the observed variations in the patterns of glomerulopathy related to socioeconomic and demographic factors include environmental factors and frequency of viral infections.[7]



The facilities to treat these patients and their treatment modalities differ vastly. Since the burden of renal diseases differs between rural and urban populations, the management is vastly different as well.[8] Here, the most common means of treating the symptoms of progressive CKD or ESRD is hemodialysis, however, Pakistan has been making stride towards the shift towards Peritoneal Dialysis since 1970 when the first center was developed in Karachi. Though the number of patients treated with PD has not been monumental when compared to the usual practice of hemodialysis.[9]

Another treatment modality for ESRD is renal ytransplant. Pakistan has been performing renal transplants for a few decades now, with the total number as many as 6553 between 1985-2021 with the help of alive relative donors.[10] The results of renal transplant and the survival of the transplant vary greatly depending on a variety of factors which are age, recurrence of the disease, HLA matching, HLA immunization, ethnic origin, duration of dialysis stay, and cardiovascular comorbidities. Renal function is influenced by all these variables and can be assessed by estimated GFR and/or proteinuria levels.[11]

Rationale

The PSN-RR will serve as a pivotal source of real-world data, propelling observational studies and clinical research in renal health. Researchers can leverage this resource to discern patterns, trends, and outcomes associated with diverse renal conditions, elevating our understanding of disease progression

and treatment efficacy. Beyond research, the registry can actively monitor renal care across varied healthcare settings, pinpointing areas for improvement to enhance patient care and outcomes. In personalized management, clinicians can tailor treatment plans based on the registry's insights into patient characteristics, treatment responses, and factors influencing renal health, ensuring an elevated overall care quality and heightened patient satisfaction. Governmental decision-makers can also utilize this data for informed choices regarding healthcare policies and resource allocation, influencing effective public health interventions against renal diseases. The registry's multifaceted impact extends to benchmarking healthcare providers, supporting comparative effectiveness research, and contributing to early detection and prevention. It fosters collaboration among institutions and continuous data collection for valuable insights into disease progression, treatment adherence, and long-term outcomes.

Objectives

i. Primary:

- To Collect a diverse range of real-world data related to renal health from multiple participating centers.
- To examine and analyze treatment outcomes to gain insights into the effectiveness of different renal health interventions.
- To provide data-driven insights to nephrologists, supporting informed clinical decision-making for personalized patient care.
- To contribute to quality improvement initiatives in renal healthcare by identifying best practices and areas for enhancement.

ii. Secondary:

- Identify trends and patterns in renal diseases, contributing to a better understanding of disease prevalence and progression.
- Enable benchmarking of healthcare practices across participating centers to assess and improve the quality of renal care.
- Provide data for public health initiatives by informing strategies for disease prevention, management, and resource allocation.
- Foster collaboration among Centers & Hospitals with renal management services, creating a network for ongoing engagement, knowledge-sharing, and collective efforts to address renal health challenges.
- Contribute to advancing medical knowledge in nephrology by generating valuable insights and evidence-based findings.
- Support evidence-based medicine by offering a comprehensive dataset for research, analysis, and potential validation of existing medical practices.

Registry Design

The PSN-RR employs a robust real-world data collection methodology, collaborating with participating centers to gain a comprehensive understanding of renal health. By partnering with many healthcare

facilities, the study captures valuable insights from a diverse cohort of patients, thereby reflecting the varied demographic profiles of individuals affected by renal diseases.

This evolving dataset yields critical insights into managing renal diseases, providing a realistic assessment of patient outcomes, treatment responses, and the progression of renal conditions within typical healthcare environments.

Regulatory and Ethical Compliance

The study' s design and implementation adhere to stringent regulatory and ethical standards. The study registry was initially submitted to the IHHN Institutional Review Board (IRB) for ethical review and subsequently submitted to the National Bioethics Committee (NBC) for further evaluation. Following approval from both bodies, the registry was officially initiated. To maintain compliance, updates on the study' s progress were regularly shared with the NBC, and the study' s ethical approval is renewed annually, ensuring ongoing adherence to ethical and regulatory requirements.

Study Population

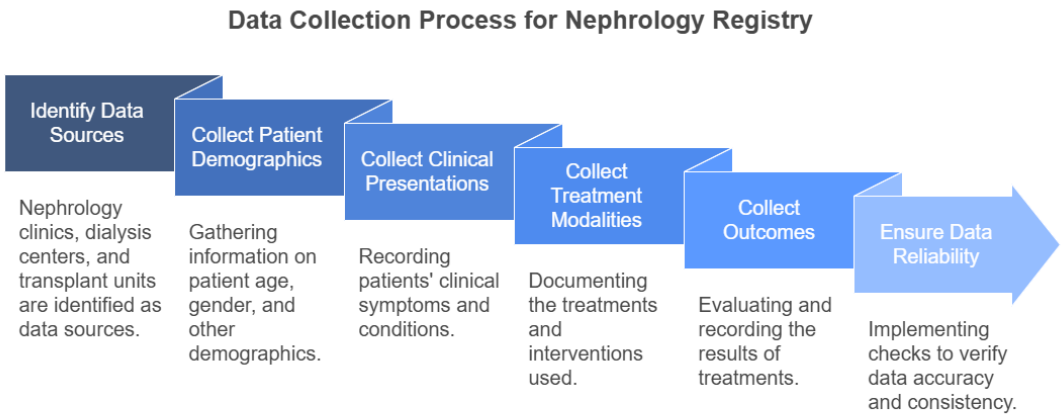
The registry enrolled patients from all over Pakistan who were diagnosed with the renal diseases from diverse demographic backgrounds who visited the participating centers for their treatments, including:

- Glomerulonephritis
- Chronic kidney disease
- Patients who have progressed to dialysis (peritoneal & hemodialysis)
- Renal transplant

Data Collection

The registry employed a comprehensive data collection methodology, gathering information from nephrology clinics, dialysis centers, and transplant units across Pakistan. Data points include patient demographics, clinical presentations, treatment modalities, and outcomes. This systematic approach ensures that the information is reliable and can be used for further research and policymaking.

Trained personnel extracted patient demographics, medical history, diagnoses, treatments, and outcomes from electronic and paper records. Quality control measures ensured accuracy in historical data, offering a thorough retrospective perspective. Continuous enrollment of new patients was seamlessly woven into routine clinical encounters. Nephrologists identified eligible participants during regular visits, obtaining their consent for participation. Data updates occurred in real-time, capturing evolving health statuses and treatment responses.



Registry Data Collection Site(s)/Location(s)

Figure 1:Data Collection process flow

Centre Name	City
Attock Hospital	Islamabad/Rawalpindi
Bahria International Hospital	Lahore
Bahria International Hospital	Islamabad/Rawalpindi
Benazir Bhutto Hospital	Rawalpindi
DHQ	Islamabad/Rawalpindi
Fatima Memorial Hospital	Lahore
Fauji Foundation Hospital	Lahore
Ghurki Trust Hospital	Lahore
Gulab Devi Hospital	Lahore
Indus Hospital	Karachi
Institute of Kidney Diseases (IKD)	Peshawar
Jinnah Hospital	Lahore
JPMC	Karachi
Khyber Teaching Hospital	Peshawar
Lady Reading Hospital	Peshawar
Life Care International Hospital	Islamabad/Rawalpindi
Multan Institute of Kidney Disease	Multan
Nawaz Sharif hospital	Lahore
Nowshera Cantonment Board Hospital Dialysis Centre	Nowshera
Pakistan Kidney and Liver Institute and Research Centre	Lahore
PIMS	Islamabad/Rawalpindi

Railway General Hospital	Islamabad/Rawalpindi
Rawal General and Dental Hospital	Islamabad/Rawalpindi
Rehman Free Dialysis Centre	Islamabad/Rawalpindi
Saidu Teaching Hospital	Swat
Services Hospital	Lahore
Surayya Azeem Hospital	Lahore
Zobia Hospital	Islamabad/Rawalpindi

Results and discussion:

Renal disease presents an escalating public health challenge in Pakistan, affecting approximately 20 million individuals suffering from chronic kidney disease (CKD). Key risk factors include diabetes, hypertension, and infections such as hepatitis B and C, which are further worsened by limited healthcare awareness and accessibility.

In a country like Pakistan, where healthcare facilities are unevenly distributed, accurately assessing the disease burden of debilitating conditions like renal diseases is critically important. This report provides a real-world assessment of data collected from various dialysis centers across the country. The data reflects a diverse array of ethnic and socioeconomic backgrounds among patients presenting with different stages of kidney disease.

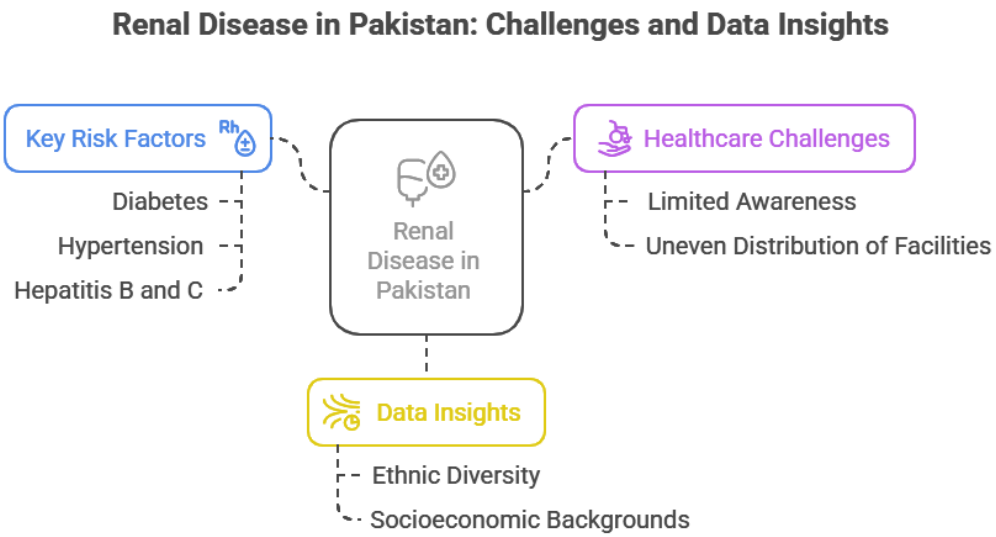


Figure 2: Challenges & Data Insights on Renal Disease in Pakistan

1. Demographics

- The dataset reveals significant gender and ethnic disparities in the prevalence of kidney-related diseases. Males are more likely to suffer from CKD (Stage 5) and Kidney Stones, while females are more prone to Acute Kidney Injury.

- **Punjabi** individuals are disproportionately affected by CKD and Glomerulonephritis, while **Urdu-speaking** individuals are more prone to Kidney Stones. This could reflect genetic, dietary, or environmental factors specific to these groups.
- **Age** plays a critical role, with Acute Kidney Injury being more common in younger individuals and CKD (Stage 3a) more prevalent in older adults.
- **Socioeconomic factors** such as income, education, and occupation may influence disease prevalence, but the high percentage of missing data limits the ability to draw strong conclusions.
- The high prevalence of **CKD (Stage 5)** suggests a need for improved early detection and treatment strategies to prevent the progression of kidney disease to advanced stages.

1.1 Gender Distribution

The current dataset includes a total of 2,155 individuals, with a clear majority being male (61.5%) compared to female (38.5%). The diseases identified according to the gender distribution are, Acute Kidney Injury observed in five cases, with a notable 80% of these cases being female, suggesting a higher prevalence of this condition among female patients. Chronic Kidney Disease (CKD), especially at Stage 5, is the most prevalent stage, impacting a total of 1,949 individuals. This condition presents a slightly higher prevalence in males, constituting 61.8% of cases compared to 38.1% in females. Glomerulonephritis impacts 57 individuals, with the distribution between genders being 43.9% female and 54.4% male. The Kidney Stones data shows that out of 22 cases, 59.1% are male, suggesting a greater prevalence of this condition in men. The gender distribution shows that males are more likely to suffer from CKD (Stage 5) and Kidney Stones, while females are more prone to Acute Kidney Injury. This could indicate gender-specific risk factors or differences in healthcare-seeking behavior.

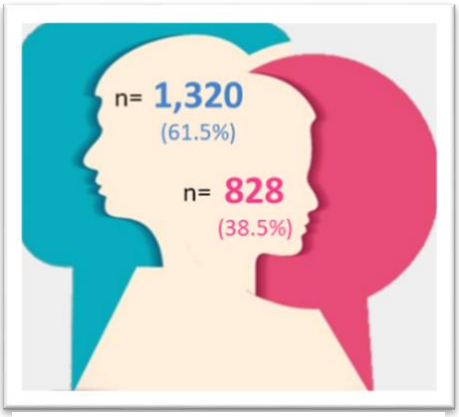


Figure 3:Gender Distribution

1.2. Age Distribution

The average age of the population is 45.0 years (±15.5), highlighting a broad age range. Acute Kidney Injury primarily affects younger individuals, with an average age of 28.6 years, whereas Chronic Kidney Disease (CKD) Stage 3a is more common in older adults, averaging 60.8 years. CKD Stage 5 and kidney stone patients have average ages close to the population mean, at 45.0 and 44.2 years, respectively. This distribution suggests that kidney-conditions vary significantly with age,

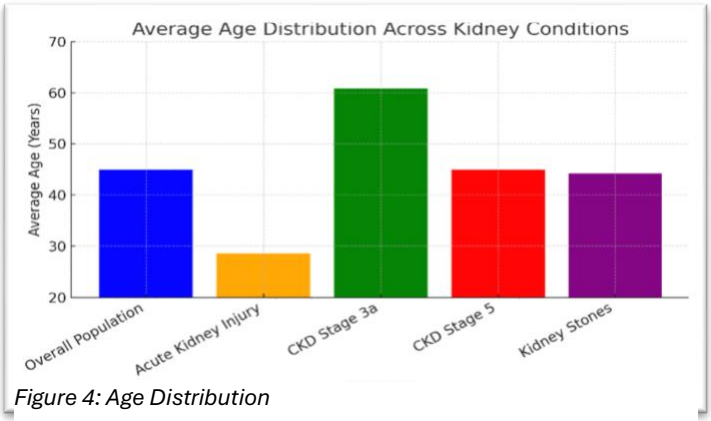


Figure 4: Age Distribution

potentially due to differing risk factors and disease progression.

1.3 Ethnicity

The current data set illustrates a variety of ethnic backgrounds among the patients, with Punjabis making up the largest group at 44.5% of the total population.

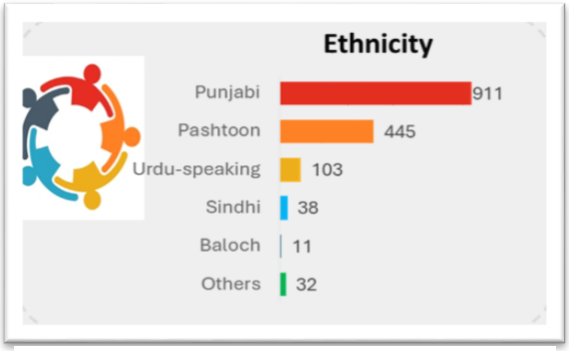


Figure 5:Ethnicity

Other significant demographics include Pashtoon at 20.1% and Urdu-speaking individuals at 4.3%. CKD Stage 5 has the most cases among Punjabi (43.7%) and Pashtoon (21.4%) individuals. Regarding Glomerulonephritis, the most affected groups are Punjabi (50.9%) and Urdu-speaking (26.3%) individuals. Kidney Stones have the highest prevalence in Urdu-speaking individuals (31.8%), followed by Punjabis (18.2%). This data indicates that Punjabi individuals are disproportionately affected by CKD (Stage 5) and Glomerulonephritis while Urdu-speaking individuals show a higher susceptibility to Kidney Stones. These trends may be influenced by genetic, dietary, or environmental factors particular to these ethnic groups.

1.4 Education

The data reveals notable trends in education levels among the studied population. Out of the total individuals, 89 (4.1%) are illiterate, while 43 (2.0%) have attained graduate-level education. However, a significant limitation of this dataset is the high proportion of missing information, with 84.6% of the education-related data unavailable, which implies that either this was not entered in patients' health information or history forms. This gap clearly restricts the ability to draw definitive conclusions about the relationship between education and health outcomes.

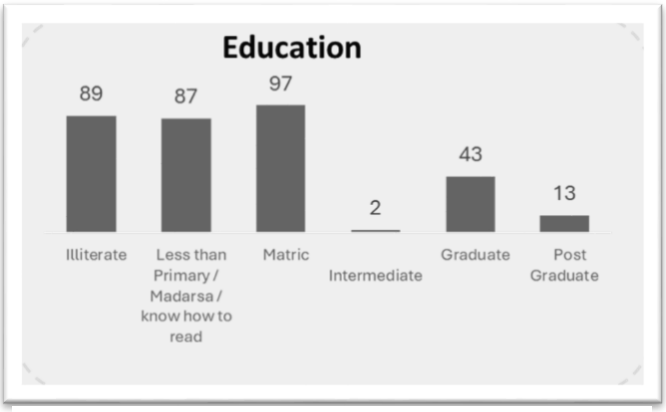


Figure 6:Education

When examining education levels by disease, distinct patterns emerge. Among individuals with CKD Stage 5, 2.3% are illiterate, and 1.4% are graduates. In contrast, for Glomerulonephritis, the proportion of illiterate individuals is significantly higher at 35.1%, while 17.5% of affected individuals are graduates. This disparity suggests that illiteracy may be a potential risk factor for Glomerulonephritis,

as a higher percentage of illiterate individuals are affected compared to those with graduate-level education.

Despite these observations, the large amount of missing data complicates the analysis. Without more complete information, it is challenging to establish a clear or conclusive relationship between education levels and the prevalence of these diseases. Further research with more comprehensive data collection is needed to validate these findings and explore the potential impact of education on disease risk.

1.5 Family Income

The income distribution among the studied population shows that 24 individuals (1.1%) fall within the lowest income bracket of 1000-10000, while 101 individuals (4.7%) earn between 10000-50000. However, the majority of the data—1,967 individuals, or 91.3%—is missing, significantly limiting the ability to analyze income patterns comprehensively.

When examining income levels by disease, notable differences emerge. Among individuals with chronic kidney disease (CKD) Stage 5, 0.4% belong to the lowest income bracket (1000-10000), and 2.3% fall within the 10000-50000 range. In contrast, for Glomerulonephritis, a much larger proportion of affected individuals are in the lower income brackets: 22.8% earn between 1000-10000, and 43.9% fall within the 10000-50000 range.

Table 1:Monthly Family Income

Monthly Family Income in PKR	Total	Female	Male
	n=2,148	n=828	n=1,320
1000-10000	24 (1.1%)	11 (1.3%)	13 (1.0%)
10000-50000	100 (4.7%)	47 (5.7%)	53 (4.0%)
50000-100000	37 (1.7%)	18 (2.2%)	19 (1.4%)
100000-above	26 (1.2%)	12 (1.4%)	14 (1.1%)

These findings suggest that lower income levels may be associated with a higher prevalence of Glomerulonephritis, as a significant percentage of affected individuals come from lower-income groups. However, the high percentage of missing income data makes it difficult to draw definitive conclusions. Further research with more complete and representative data is needed to better understand the relationship between income levels and disease prevalence.

1.6 Marital Status

241 individuals, accounting for 11.2% of the participants, are married. In contrast, 75 individuals are single, making up 3.5% of the population in this sample. A significant portion—1,821 individuals (84.5%) lack information regarding their marital status. When analyzing marital status in relation to specific diseases, the findings present some interesting trends. Among individuals affected by CKD Stage 5, approximately 7.6% are married, while 2.4% identify as single. In comparison, those suffering from Glomerulonephritis show a striking difference, with 71.9% of affected individuals being married and 19.3% being single. These statistics imply that married individuals may be more likely to be affected by Glomerulonephritis, given the significant percentage of married individuals within this group. However, it is important to note that the substantial percentage of missing data hampers the ability to draw definitive conclusions about the relationship between marital status and disease prevalence.

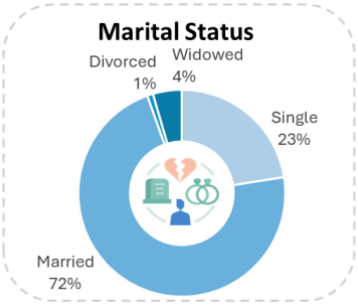


Figure 7:Marital Status

1.7. Occupation

110 individuals, accounting for 5.1% of the sample, are currently unemployed. Additionally, there are 90 housewives, representing 4.2% of the population surveyed. A substantial portion of the data, specifically 1,849 individuals, or 85.8%, had missing information regarding their occupation.

When examining occupation in relation to specific diseases, the data reveals noteworthy trends. For individuals with CKD Stage 5, 4.0% are unemployed, while 3.3% are housewives. In contrast, for those affected by glomerulonephritis, the situation differs significantly; 19.3% of affected individuals are unemployed, whereas 12.3% are housewives. This discrepancy suggests that unemployment may pose a higher risk factor for individuals suffering from glomerulonephritis, as a more significant percentage of unemployed individuals are impacted compared to those who are housewives. However, it is essential to note that the substantial amount of missing data limits the ability to draw firm, definitive conclusions from these observations.

1.8. Socioeconomic Class

The distribution of socioeconomic classes among individuals with specific diseases reveals interesting patterns. For Chronic Kidney Disease (CKD) Stage 5, 0.5% of affected individuals belong to SEC A, while 0.8% are in SEC B. In contrast, for Glomerulonephritis, none of the affected individuals (0.0%) fall into SEC A, but 3.5% are categorized under SEC B.

These findings suggest that individuals in lower socioeconomic classes, particularly SEC B, may be more susceptible to Glomerulonephritis, as a higher percentage of affected individuals are found in this group compared to SEC A. However, it is important to note that the analysis is constrained by a significant amount of missing data, which limits the ability to establish a clear or definitive relationship between socioeconomic class and disease prevalence. Further research with more comprehensive and complete datasets is necessary to validate these observations and explore the potential impact of socioeconomic factors on disease risk.

1.9. Disease-Specific Insights

Chronic Kidney Disease (CKD): CKD (Stage 5) is the most prevalent stage, affecting 1,949 individuals (90.4% of CKD cases). This indicates that most CKD cases are in the advanced stage, which may reflect late diagnosis or limited access to early treatment. CKD (Stage 4) affects 17 individuals, while CKD (Stage 3b) affects 12 individuals, gradually decreasing prevalence as the disease progresses to earlier stages.

Acute Kidney Injury: Five individuals have been affected, with 80% of them being female. This observation suggests that females may exhibit a higher susceptibility to this condition, potentially attributable to factors such as complications related to pregnancy or autoimmune diseases.

Glomerulonephritis: 57 individuals are affected, with a near-equal gender distribution (43.9% female, 54.4% male). This condition affects both genders almost equally, indicating that gender-specific factors may not strongly influence it.

Kidney Stones: Individuals are affected, with a higher prevalence in males (59.1%). This aligns with global trends, where men are more likely to develop kidney stones due to factors such as diet, dehydration, and metabolic differences.

Polycystic Kidney Disease (PKD): 5 individuals are affected, with 80% being male. This suggests that males may be more prone to PKD, although the small sample size limits the ability to draw definitive conclusions.

Table 2: Disease-specific Insights

	No. of Patients	Female	Male
	n=2,155	**828 (38.4%)**	**1,320 (61.3%)**
Acute Kidney Injury	5	4 (80.0%)	1 (20.0%)
CKD (Stage 2)	1		1 (100.0%)
CKD (Stage 3a)	4	2 (50.0%)	2 (50.0%)
CKD (Stage 3b)	12	6 (50.0%)	6 (50.0%)
CKD (Stage 4)	17	7 (41.2%)	10 (58.8%)
CKD (Stage 5)	1,949	743 (38.1%)	1,205 (61.8%)
CKD (Stage unknown)	25	11 (44.0%)	13 (52.0%)
Glomerulonephritis	57	25 (43.9%)	31 (54.4%)
Kidney Infection (Pyelonephritis)	7	3 (42.9%)	4 (57.1%)
Kidney Stones	22	8 (36.4%)	13 (59.1%)
Polycystic Kidney Disease (PKD)	5	1 (20.0%)	4 (80.0%)
Vesicoureteral reflux (VUR)	4		4 (100.0%)
Missing	47	18 (38.3%)	26 (55.3%)

2. Comorbidities

2.1 Prevalence of Diabetes and Hypertension

Diabetes emerged as one of the most common comorbidities in this patient population, affecting 47.9% of the total patients (1,033 out of 2,155). The prevalence of diabetes is exceptionally high among patients with advanced stages of chronic kidney disease (CKD). In CKD Stage 5, 50.3% of patients (981 out of 1,949) have diabetes. Similarly, diabetes is present in 100% of patients in CKD Stage 3a (4 out of 4) and 50% in CKD Stage 3b (6 out of 12). This significant prevalence of diabetes among CKD patients highlights the well-documented connection between diabetes and kidney disease. Diabetes is a leading cause of CKD, and its high occurrence in this population underscores the importance of managing diabetes to prevent or slow the progression of kidney disease. The data further emphasizes the need for targeted interventions and monitoring for diabetic patients, particularly those in advanced stages of CKD, to mitigate the risk of further complications.

Hypertension shows a significantly higher prevalence than diabetes in this patient cohort, impacting 66.4% of the total population (1,430 out of 2,155). As a well-known modifiable risk factor for the development and progression of chronic kidney disease (CKD), hypertension has a notable prevalence across all CKD stages. Specifically, in CKD Stage 3b, 91.7% of patients (11 out of 12) have hypertension, whereas in CKD Stage 4, the prevalence is 76.5% (13 out of 17). Among patients with CKD Stage 5, 67.4% (1,314 out of 1,949) are diagnosed with hypertension. These findings emphasize the widespread burden of hypertension in CKD populations and its critical role in the decline of renal function. The strong link between hypertension and CKD progression underscores the need for strict blood pressure control as a cornerstone of therapeutic management. Effectively managing hypertension is crucial not only for slowing the decline of renal function but also for reducing the associated cardiovascular morbidity and mortality risks, which are disproportionately high in CKD patients. This data stresses the importance of systematic monitoring, early pharmacological and non-pharmacological interventions, and following evidence-based treatment guidelines. Optimizing blood pressure management in CKD patients is a key strategy for improving clinical outcomes, reducing complications, and enhancing long-term prognosis in this high-risk population.

2.2. Combination of Comorbidities

Diabetes and Hypertension: This is the most common combination, affecting 17.9% of the total patient population (386 out of 2,155). This combination is particularly concerning as both conditions accelerate kidney damage.

Diabetes, Hypertension, and ischemic heart disease: This trio of comorbidities affects 25.2% of the total patient population (542 out of 2,155). Patients with this combination are at very high risk for cardiovascular events and kidney failure.

Hypertension and Hepatitis C Virus (HCV): Found in 1.6% of patients (34 out of 2,155), this combination underscores the need for meticulous management of both blood pressure and liver health in CKD patients.

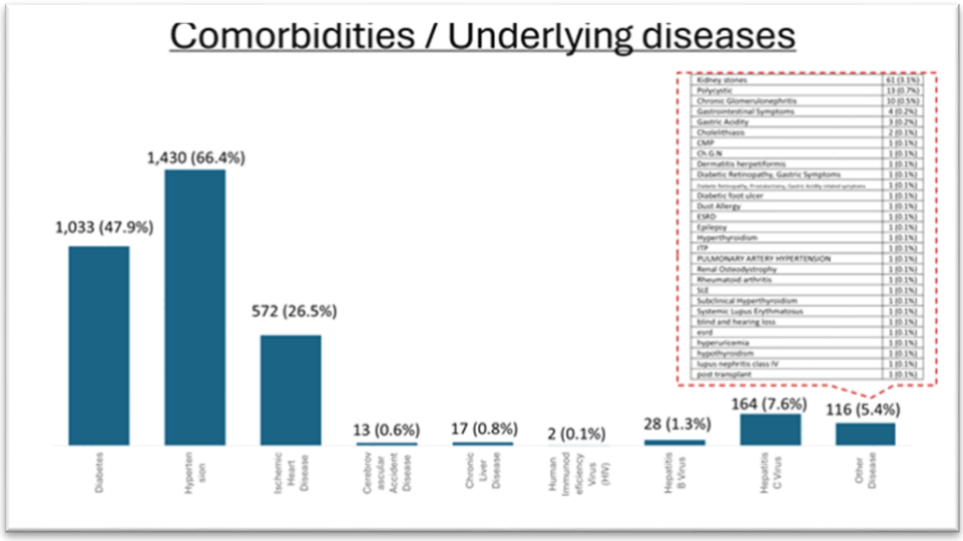


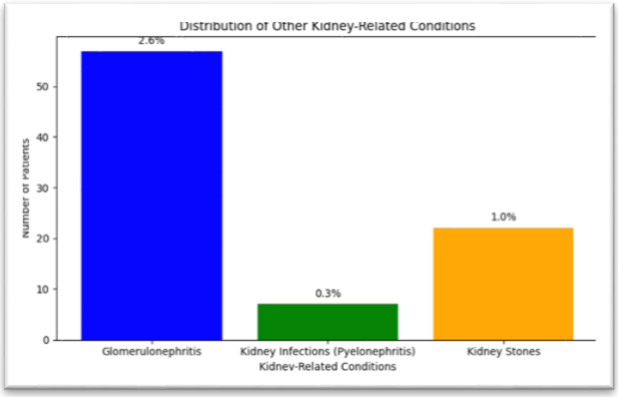
Figure 8:Co-Morbidities

2.3. Chronic Kidney Disease (CKD) Stages

The high number of patients in CKD Stage 5 suggests that many patients are in advanced stages of kidney disease, which may require dialysis or kidney transplantation. The lower numbers in earlier stages (e.g., Stage 3a and 3b) may indicate underdiagnosis or a lack of early detection of CKD.

2.4. Other Kidney-Related Conditions

- Glomerulonephritis: This condition, which involves inflammation of the kidney's filtering units, affects 57 patients (2.7% of the total population) and is more common in patients with CKD Stage 5 (50.3%).
- Kidney Infections (Pyelonephritis): Reported in 7 patients (0.3%), kidney infections are relatively rare but can lead to serious complications if not treated promptly.
- Kidney Stones: Present in 22 patients (1.0%), kidney stones can cause significant pain and may contribute to kidney damage if recurrent.



- *Figure 9: Distribution of other Kidney Related Conditions*

Table 3: Treatment for CKD Stages and other renal diseases The dataset categorizes patients into different stages of CKD, with the majority of patients being in **CKD Stage 5** (end-stage renal disease)**, CKD Stage 5**: 1,946 patients (91.0% of the total population)**, CKD Stage 4**: 17 patients (0.8%)**, CKD Stage 3b**: 12 patients (0.6%)**, CKD Stage 3a**: 4 patients (0.2%).

	Non Dialysis	Peritoneal Dialysis (PD)	Hemodialysis (HD)	Renal Transplant	Total
	n=26	n=66	n=2,031	n=16	n=2,139
AKI	1 (3.8%)	2 (3.0%)	2 (0.1%)	0 (0.0%)	5 (0.2%)
CKD (Stage 2)	0 (0.0%)	0 (0.0%)	1 (0.0%)	0 (0.0%)	1 (0.0%)
CKD (Stage 3a)	2 (7.7%)	1 (1.5%)	1 (0.0%)	0 (0.0%)	4 (0.2%)
CKD (Stage 3b)	4 (15.4%)	5 (7.6%)	3 (0.1%)	0 (0.0%)	12 (0.6%)
CKD (Stage 4)	2 (7.7%)	10 (15.2%)	5 (0.2%)	0 (0.0%)	17 (0.8%)
CKD (Stage 5)	1 (3.8%)	36 (54.5%)	1,895 (93.3%)	14 (87.5%)	1,946 (91.0%)
CKD(UKS)	1 (3.8%)	0 (0.0%)	23 (1.1%)	1 (6.2%)	25 (1.2%)
GN	9 (34.6%)	6 (9.1%)	41 (2.0%)	1 (6.2%)	57 (2.7%)
Pyleonephritis	0 (0.0%)	0 (0.0%)	7 (0.3%)	0 (0.0%)	7 (0.3%)
Kidney Stones	5 (19.2%)	4 (6.1%)	13 (0.6%)	0 (0.0%)	22 (1.0%)
PKD	1 (3.8%)	0 (0.0%)	4 (0.2%)	0 (0.0%)	5 (0.2%)
VUR	0 (0.0%)	2 (3.0%)	2 (0.1%)	0 (0.0%)	4 (0.2%)
Missing	0 (0.0%)	0 (0.0%)	34 (1.7%)	0 (0.0%)	34 1.6%)

CKD: chronic kidney disease, CKD(UKS): CKD unknown stage, GN: glomerulonephritis, PKD: polycystic kidney disease., VUR: vesicoureteric reflux, IHD: ischemic heart disease, CVA: cerebrovascular accident, CLD: chronic liver disease, HIV: hummun immunodeficiency virus, HBsAg: Hepatitis B virus Ag, HCV: Hepatits C virus.

2.5. Less Common Comorbidities

- Polycystic Kidney Disease (PKD): A genetic disorder causing cysts to form in the kidneys, PKD is reported in 5 patients (0.2%). While rare, PKD can lead to kidney failure over time.
- Vesicoureteral Reflux (VUR): This condition, where urine flows backward from the bladder into the kidneys, is present in 4 patients (0.2%). VUR is more common in children but can also affect adults.

2.6. Other Systemic Diseases

- Ischemic Heart Disease: Present in 26.5% of the total patient population (572 out of 2,155), ischemic heart disease is a significant comorbidity in CKD patients. It is particularly prevalent in CKD Stage 5 (28.2%).

- Cerebrovascular Accident Disease (Stroke): Relatively rare, affecting only 0.6% of patients (13 out of 2,155). However, stroke risk is higher in CKD patients due to shared risk factors like hypertension and diabetes.
- Chronic Liver Disease: In 0.8% of patients (17 out of 2,155), chronic liver disease can complicate management of kidney disease due to the interplay between liver and kidney function.
- Hepatitis C Virus (HCV): HCV infection is present in 7.6% of patients (164 out of 2,155), with a higher prevalence in CKD Stage 5 (7.3%). HCV is a significant concern in CKD patients, especially those on dialysis, due to the risk of liver damage and increased mortality.
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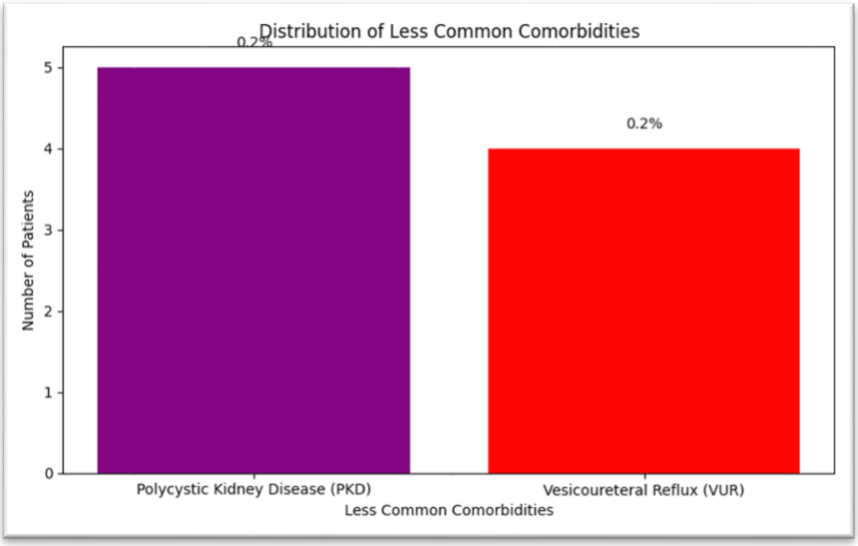


Figure 10: Distribution of Less Common Co-Morbidities

2.7. Rare Conditions

- Conditions such as Dermatitis herpetiformis, Diabetic Retinopathy, and Systemic Lupus Erythematosus (SLE) are extremely rare, each affecting only 1 patient (0.0%). While rare, these conditions can significantly impact patient health and require specialized care.

3. Missing Data

There are 47 patients (2.2%) with missing data about their kidney condition. This missing information could represent a limitation in the dataset, as it may influence the accuracy of the analysis. Future studies should make efforts to ensure complete data collection.

4. Disease Progression (renal)

The kidney disease observed in the patients' data showed different disease progression outcomes. The total data was divided into the following categories:

- No Progression: 62.1% (1,328 patients) of the total cases showed no disease progression. This was highest among patients on Medicine (84.6%) and lowest among PD patients (4.5%).
- Unknown Progression: 25.1% (536 patients) had unknown progression status, with the highest percentage in Renal Transplant patients (68.8%).

- Yes Progression: 12.3% (263 patients) experienced disease progression, with the highest percentage in PD patients (95.5%).
-

Table 4: Co-Morbidities with Kidney Diseases

The dataset categorizes patients into different stages of CKD, with the majority of patients being in **CKD Stage 5** (end-stage renal disease)**, CKD Stage 5**: 1,946 patients (91.0% of the total population)**, CKD Stage 4**: 17 patients (0.8%)**, CKD Stage 3b**: 12 patients (0.6%)**, CKD Stage 3a**: 4 patients (0.2%).

	No. of Patients	IHD	CVA	CLD	HIV	HBsAg	HCV
	n=2,155	572 (26.5%)	13 (0.6%)	17 (0.8%)	2 (0.1%)	28 (1.3%)	164 (7.6%)
AKI	n=5						
CKD (Stage 2)	n=1	1 (100%)					
CKD (Stage 3a)	n=4	1 (25.0%)					
CKD (Stage 3b)	n=12	3 (25.0%)	2 (16.7%)	1 (8.3%)		1 (8.3%)	
CKD (Stage 4)	n=17	3 (17.6%)	1 (5.9%)		1 (5.9%)		1 (5.9%)
CKD (Stage 5)	n=1,949	549 (28.2%)	9 (0.5%)	12 (0.6%)	1 (0.1%)	25 (1.3%)	142 (7.3%)
CKD(UKS)	n=25	2 (8.0%)					1 (4.0%)
GN	n=57	9 (15.8%)	1 (1.8%)	1 (1.8%)			12 (21.1%)
Pyleonephritis	n=7	1 (14.3%)					
Kidney Stones	n=22	3 (13.6%)		3 (13.6%)		1 (4.5%)	5 (22.7%)
PKD	n=5						2 (40.0%)
VUR	n=4						1 (25.0%)
Missing	n=47					1 (2.1%)	

CKD: chronic kidney disease, CKD(UKS): CKD unknown stage, GN: glomerulonephritis, PKD: polycystic kidney disease., VUR: vesicoureteric reflux, IHD: ischemic heart disease, CVA: cerebrovascular accident, CLD: chronic liver disease, HIV: hummun immunodeficiency virus, HBsAg: Hepatitis B virus Ag, HCV: Hepatits C virus.

5. Treatment modalities

5.1 CKD (Stage 5):

The primary treatment modality for these patients was Hemodialysis (HD), with 93.3% of Stage 5 CKD patients undergoing this treatment. Hemodialysis is a life-sustaining therapy that filters waste and excess fluids from the blood when the kidneys are no longer able to perform this function.

5.2 Glomerulonephritis:

The highest percentage of these patients (34.6%) were treated with Medicine, denoting those pharmacological interventions, such as immunosuppressive therapy or anti-inflammatory drugs, were the primary approach for managing this condition.

5.3 Kidney Stones:

The most common treatment modality for kidney stones was Medicine (19.2%), indicating that non-invasive approaches, such as pain management, hydration, and medications to facilitate stone passage,

were frequently used. In some cases, more invasive procedures like lithotripsy or surgical removal may be required, but the data indicates a preference for medical management in this cohort.
Hemodialysis (HD) is the predominant treatment for Stage 5 CKD, reflecting the critical need for renal replacement therapy in end-stage kidney disease. However, medicine is the primary treatment for glomerulonephritis and kidney stones, highlighting the role of pharmacological management in these conditions. The data underscores the importance of tailored treatment approaches based on the specific kidney condition and its severity.

Table 5: Disease Progression among chronic kidney disease patients.

	Total	Acute Kidney Injury	CKD (Stage 2)	CKD (Stage 3a)	CKD (Stage 3b)	CKD (Stage 4)	CKD (Stage 5)	CKD (Stage unknown)	Glomerulonephritis	Kidney Infection (Pyelonephritis)	Kidney Stones	Polycystic Kidney Disease (PKD)	Vesicoureteral reflux (VUR)	Missing
	n=2,155	n=5	n=1	n=4	n=12	n=17	n=1,949	n=25	n=57	n=7	n=22	n=5	n=4	n=47
b- Has the disease progressed?														
Yes	263 (12.2%)	3 (60.0%)		2 (50.0%)	5 (41.7%)	11 (64.7%)	194 (10.0%)	1 (4.0%)	18 (31.6%)	4 (57.1%)	15 (68.2%)	4 (80.0%)	4 (100.0%)	2 (4.3%)
No	1,330 (61.7%)	1 (20.0%)	1 (100.0%)	2 (50.0%)	7 (58.3%)	6 (35.3%)	1,243 (63.8%)	22 (88.0%)	34 (59.6%)	3 (42.9%)	7 (31.8%)	1 (20.0%)		3 (6.4%)
Fluid Retention	182 (8.4%)	2 (40.0%)		1 (25.0%)	3 (25.0%)	5 (29.4%)	139 (7.1%)	1 (4.0%)	15 (26.3%)	1 (14.3%)	9 (40.9%)	1 (20.0%)	3 (75.0%)	2 (4.3%)
High Blood Pressure	144 (6.7%)				4 (33.3%)	6 (35.3%)	114 (5.8%)	1 (4.0%)	7 (12.3%)		6 (27.3%)	2 (40.0%)	2 (50.0%)	2 (4.3%)
Pulmonary Edema	51 (2.4%)				1 (8.3%)	2 (11.8%)	41 (2.1%)	1 (4.0%)	4 (7.0%)		2 (9.1%)			
Hyperkalemia	40 (1.9%)	1 (20.0%)			2 (16.7%)	2 (11.8%)	30 (1.5%)	1 (4.0%)	2 (3.5%)		1 (4.5%)		1 (25.0%)	
Anemia	181 (8.4%)			1 (25.0%)	3 (25.0%)	10 (58.8%)	142 (7.3%)		8 (14.0%)	3 (42.9%)	7 (31.8%)	2 (40.0%)	3 (75.0%)	2 (4.3%)
Decreased Urine Output	165 (7.7%)	2 (40.0%)		1 (25.0%)	4 (33.3%)	4 (23.5%)	134 (6.9%)		9 (15.8%)	2 (28.6%)	5 (22.7%)	1 (20.0%)	2 (50.0%)	1 (2.1%)
Further Deterioration Kidney Function	59 (2.7%)	1 (20.0%)		2 (50.0%)	5 (41.7%)	7 (41.2%)	32 (1.6%)		5 (8.8%)	1 (14.3%)	4 (18.2%)		2 (50.0%)	
Ischemic Heart Disease	13 (0.6%)					2 (11.8%)	9 (0.5%)				2 (9.1%)			
Atherosclerotic Disease	1 (0.0%)						1 (0.1%)							
Cerebrvascular Disease	2 (0.1%)						2 (0.1%)							
Other Disease Progressed	29 (1.3%)						27 (1.4%)					2 (40.0%)		

5.4 Complications

In the available data, the treatment options (medicine, peritoneal dialysis, and hemodialysis) led to complications observed in a total of 263 (12.3%) patients out of 2,139 patients. From these, the complications observed were as follows:

- **Fluid Retention**: 8.5% (182 patients) experienced fluid retention, most commonly in PD patients (53.0%).
- **High Blood Pressure**: 6.7% (144 patients) had high blood pressure, with the highest prevalence in PD patients (43.9%).
- **Pulmonary Edema**: 2.4% (51 patients) reported pulmonary edema, most frequently in PD patients (12.1%).
- **Hyperkalemia**: 1.9% (40 patients) had hyperkalemia, with the highest occurrence in PD patients (16.7%).
- **Anemia**: 8.5% (181 patients) experienced anemia, most commonly in PD patients (56.1%).
- **Decreased Urine Output**: 7.7% (165 patients) had decreased urine output, with the highest percentage in PD patients (62.1%).
- **Further Deterioration of Kidney Function**: 2.8% (59 patients) experienced further deterioration, predominantly in PD patients (81.8%).

6. Distribution of treatment modalities as per the patient's age

Among the total patient population, 38.4% were female, with the highest proportion in Peritoneal Dialysis (PD) patients (51.5%), while 61.4% were male, most commonly undergoing Hemodialysis (HD) (61.9%). Age-wise, 1.7% were 14 years or younger, with PD being the preferred modality (19.7%). Among those aged 15-24 (7.6%), Renal Transplant was most common (25.0%). In the 25-34 (18.1%) and 35-44 (19.8%) age groups, HD was dominant (18.5% and 20.2%, respectively). HD remained the primary choice for 45-54-year-olds (22.6%) and was prevalent in 55-64-year-olds (17.3%), though this group saw a notable shift toward Medicine (30.8%). Among those 65 and older (11.0%), PD was the most utilized treatment (21.2%). A total of 188 deaths were recorded, including four due to peritonitis.

Table 6: Distribution of Treatment Modalities per patient Age

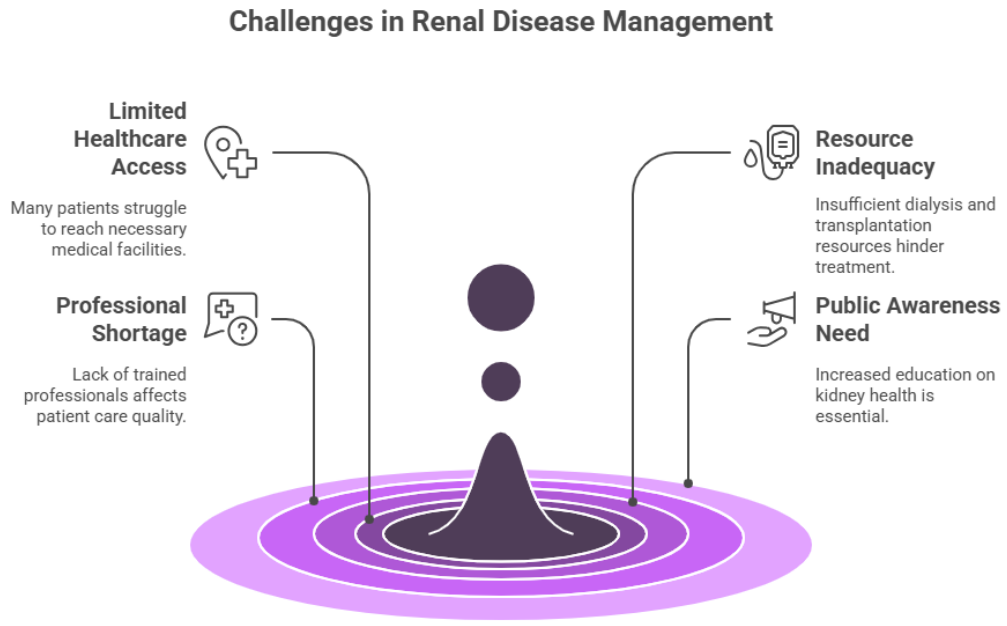
	Total	Medicine	Peritoneal Dialysis (PD)	Hemodialysis (HD)	Renal Transplant
Age groups	n=2,139	n=26	n=66	n=2,031	n=16
14 & below	36 (1.7%)	1 (3.8%)	13 (19.7%)	21 (1.0%)	1 (6.2%)
15-24	162 (7.6%)	1 (3.8%)	6 (9.1%)	151 (7.4%)	4 (25.0%)
25-34	387 (18.1%)	0 (0.0%)	7 (10.6%)	376 (18.5%)	4 (25.0%)
35-44	424 (19.8%)	4 (15.4%)	7 (10.6%)	411 (20.2%)	2 (12.5%)
45-54	474 (22.2%)	5 (19.2%)	7 (10.6%)	458 (22.6%)	4 (25.0%)
55-64	370 (17.3%)	8 (30.8%)	12 (18.2%)	350 (17.2%)	0 (0.0%)
65 & above	236 (11.0%)	5 (19.2%)	14 (21.2%)	217 (10.7%)	0 (0.0%)
Missing	50 (2.3%)	2 (7.7%)	0 (0.0%)	47 (2.3%)	1 (6.2%)
Age year	45.0 (±15.5)	53.0 (±15.9)	41.4 (±24.8)	45.1 (±15.1)	32.9 (±12.8)

Recommendations

1. Enhanced Management of Diabetes and Hypertension: Given their high prevalence, targeted interventions to manage diabetes and hypertension can significantly improve outcomes in patients with kidney disease. This includes regular monitoring, lifestyle modifications, and appropriate medication.
2. 1. Screening for Hepatitis C: Considering the relatively high prevalence of HCV in this population, routine screening and treatment for HCV may be beneficial, particularly in CKD Stage 5 patients.
3. 2. Further Research on Rare Conditions: More research is necessary to understand the impact of rare conditions like PKD and VUR on the progression of kidney disease. This could lead to improved diagnostic tools and treatment options for these patients.
4. Addressing Missing Data: Efforts should be made to ensure complete data collection in future studies to enhance the accuracy of the analysis and provide a more comprehensive understanding of comorbidities in kidney disease patients.

Challenges

Despite the establishment of the registry, several challenges persist in the management of renal diseases in Pakistan. These include limited access to healthcare facilities, inadequate resources for dialysis and transplantation, and a shortage of trained healthcare professionals. Additionally, there is a need for increased public awareness regarding kidney health and preventive measures. With limited awareness and healthcare facilities, collecting real-world data also becomes a challenge as physicians and patients need to realize how important this extra step is in collecting the data.



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TERM OF REFERENCE FOR PSN RENAL REGISTRY COMMITTEE

DEFINITIONS:

Registry: A registry is a collection of information about individuals, usually focused on a specific diagnosis or condition. A place or office where registers or records are kept:

ABBREVIATIONS:

PSN: Pakistan society of nephrology
PSNRRC: Pakistan Society of Nephrology Renal Registry Committee

CRO/SMO: Contract research organization, Site Management organization

PJKD: Pakistan journal of kidney diseases

TORs: Terms of Reference

1. FORUM MANDATE:

The purpose of this committee is to facilitate and help stream clinical data with the CRO/SMO. The committee will also take all measures to protect data and to review the research projects by contributing hospitals and personnel.

2. MEMBERSHIP:

The PSNRRC will comprise of the following 11 members:

2.1. Chair PSNRRC

2.2. Secretary PSNRRC

2.3. Representatives from all four provinces and Islamabad

2.4. The selection of members will be as follows: 3 from Punjab (1 from the south, 1 from the north, and 1 from the center) 2 from Sind (1 from

Karachi and 1 from the interior) 1 from KPK and 1 from Baluchistan

2.5. Representative CRO/SMO

2.6. Representative from the PSN Executive Committee.

3. CHAIR:

The chair of the Committee will be an elected PSN member selected/elected by PSN ECC and he/she will report to the President of the PSN

4. SECRETARY:

A representative from PSN ECC will be the secretary of the Committee. He / She will be responsible for scheduling meetings and taking the minutes.

5. TENURE AND REAPPOINTMENT OF CHAIRS AND MEMBERS:

The tenure of membership for the faculty shall be three (3) years. They may be reappointed for another consecutive term, the continuation of membership not exceeding two (2) terms consecutively. They can be reappointed after a gap of one term. The tenure for other members would last the duration of the appointment under a specific designation.

6. MEETING SCHEDULE:

The PSNRRC will meet quarterly or as decided by the Committee Chair.

7. PARTICIPATION:

The quorum for a meeting is set at 50% attendance of the members.

8. METHOD OF DECISION MAKING:

Decision-making will be by consensus.

9. REPORTING RELATIONSHIP:

The PSNRRC will report its activities and outcomes to the President through sending regular minutes.

10. CORE FUNCTIONS/DELIVERABLES:

10.1. To maintain harmony among participating centers and to set minimal annual research targets for each hospital as well as maintaining a central log of all published research through its secretary.

10.2. To develop the capacity to run the registry by PSN itself and develop a team at the national level in participating hospitals to replace the job of CRO/SMO

10.3. To increase the scope of the PSNRRC and to collaborate with other national and international registries.

10.4. To develop research Guidance for researchers and work out a simple research request form, merge the data request form and standard analysis form along with data query tools for incidence, prevalence, mortality, and hospitalization with CRO

10.5. To present a quarterly report to the PSN President

10.6. To issue data on important findings to awareness and adequacy task force for dissemination on different public social media and on the website.

10.7. To publish its quarterly report to PJKD

11. **RESPONSIBILITY:**
PSNRRC Committee

12. **RIGHTS OF ACCESS:**
PSN President and general secretary and Chair and secretary PSNRRC