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Pakistan Renal Data System (PKRDS): First Annual Report

Maryam Javed, Azhar Ali Khan, Mateen Akram, Waqar Ahmed.

Department of Nephrology,
Shaikh Zayed Hospital, Lahore, Pakistan

Abstarct:

Care of patients with chronic illnesses is a challenge. Several care management processes utilize different tools and protocols for maintaining a meaningful follow up and devise interventions. Clinical registries are one aspect of such management process and provide in depth look into the real-life presentations and management issues and needs of chronic diseases. Registries for kidney diseases are being maintained since long in the developed countries. Pakistan renal data system (PKRDS) is an effort in the same direction to maintain and acquire electronic data. The current review is the first report from the PKRDS.

Key words: *Kidney diseases, registry, chronic diseases, hemodialysis, transplantation, peritoneal dialysis, hepatitis, seroconversion.*

Corresponding Author

Professor Dr Waqar Ahmad
Head Department of Nephrology
Shaikh Zayed Hospital, Lahore

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Introduction:

Care management processes utilize different management systems, protocols, data collections and information systems to improve the care of the patients.[1] Wagner proposed a chronic care model to effectively provide care for the chronic diseases.[2,3]
Registries for chronic diseases are clinical management processes, maintained to gather information on a wide aspect or on a particular aspect of a disease. A disease registry is a computer application used to capture, manage, and provide information on specific conditions to support organized care management of patients with chronic disease[1]

The registries have evolved into strong tools to guide the physicians, health care providers and health policy making bodies to understand the different aspects of the disease in a large population of patients. A computerized disease registry includes critical information about each patient and the performance and results of important aspects of care.[3]
These data in fact, provide a real-life data on the presentation and intervention effects of the chronic diseases.[4]

It also identifies the gaps in management and provide direction for unmet needs in the care of the patients. Financial aspect of chronic diseases requiring fund allocation are better defined and long-term plans could be implemented through this. The clinical care model and registries help in promoting consistent financing, develop and allocate human resources appropriately.[5]

United State Renal Data System is one of the largest registries maintaining all the critical information about chronic kidney disease patients on renal replacement therapy.[6] List of publications and interventions based on this registry is huge and impressive. In fact the editorial by Port and Held marking the 30 years of USRDS data summarizes the usefulness of registries: "Thus, the USRDS has contributed in many important ways to advancing knowledge and improving patient care and will continue to be an indispensable data resource for clinicians, investigators, and policy makers".[7]

Keeping in view of the prevalent CKD situation in Pakistan, Pakistan Renal Data System (PKRDS) was initiated in 2018 to keep a proper record of End stage kidney Disease (ESKD) patients throughout Pakistan. It was endorsed by the Pakistan Society of Nephrology as an important tool to acknowledge the extent of the Dialysis population.

PKRDS First Report:

Here, we present our first analysis of data from PKRDS after collecting extensive information from different centres of the country. We acknowledge the fact that it would not have been possible without the understanding and willingness of 31 contributing centers. Table-1 represents the total 31 registered hemodialysis (HD) units according to their province-wise location throughout Pakistan. It also shows the cumulative number (n=658) of HD machines that were further categorized into hepatitis positive and negative machines. The supervision of these HD units was done either by a nephrologist or urologist. Government was the main sponsoring body for these patients whereas departments and non-governmental organizations (NGO's) were among the other funding sources.

Table-2 and 3 show the baseline demographic and laboratory characteristics of patients enrolled in PKRDS registry. This first report included 990 patients with the mean age 46.6 ± 15.2 years. The causes of ESRD, vascular access for dialysis and hepatitis status are also shown in this table.

Table 1: Details of contributing centers to the dialysis registry according to the geographical area, number of machines, hepatitis status and administrative and financial coverage.

	Numbers (n)	Percentage (%)
Total Hemodialysis units	31	
Punjab	26	83
Sindh	4	12.9
Khyber Pakhtunkhawa	2	6.0
Federal Capital Area	2	6.0
Total no. of Machines	658	
Hepatitis – ve	440	29
Hepatitis C +ve	191	4.0
Hepatitis B+ve	27	66
Sponsoring Organizations		
Government	577	58.3
Departments	113	11.4
Trusts	186	18.6
Self	112	11.4
Others	2	0.2
Supervision by		
Nephrologist	28	90.3
Urologist	2	6.4
Staff Nurse	1	3.0

Table 2: Patients clinical characteristics included in the PKRDS registry

	Number	Percentage (%)
Total ESKD* Patients	990	
Mean age (years)	46.6±15.2 years	
Cause of ESRD		
Diabetic Nephropathy	327	33.0
Hypertension	317	32.0
Glomerulonephritis	71	7.2
Stones	31	3.1
Polycystic kidney disease	2	0.2
Others	105	10.6
Vascular Access		
AVF#	880	88.9
AVG$^{@}$	10	1.0
Temporary Catheter	63	6.4
Permanent Catheter	35	3.5
Unknown	1	0.1
Hepatitis C Status		
Anti HCV +ve	437	44.1
Anti HCV – ve	531	53.6
Unknown	22	2.2
HCV PCR +ve	302	69.1
Hepatitis B status		
HBsAg +ve	14	1.4
HBsAg – ve	877	88.6
Unknown	99	10.0

*ESKD: End stage kidney disease, $^{\#}$AVF: Arteriovenous fistula, $^{@}$AVG: Arteriovenous graft

Table-3 represents the mean laboratory values of Hb, BUN, Creatinine, Calcium, Phosphate, intact PTH and serum Albumin in patients undergoing hemodialysis in our registered centres.

	Mean	Standard Deviation
Hemoglobin (g/dl)	10.00	1.87
BUN (mg/dl)	91.7	44.5
Creatinine (mg/dl)	8.99	3.4
Calcium (mg/dl)	8.0	1.14
Phosphate (mg/dl)	5.4	1.94
Intact PTH (pg/l)	602.5	603.6
Albumin (g/dl)	3.3	0.72

Figure-1 describes the gender distribution of our dialysis patients whereas figure-2 reflects their weekly frequency of HD sessions. Hepatitis B vaccination status is shown in Figure-3.

Figure 1: Gender distribution among the PKRDS patients.

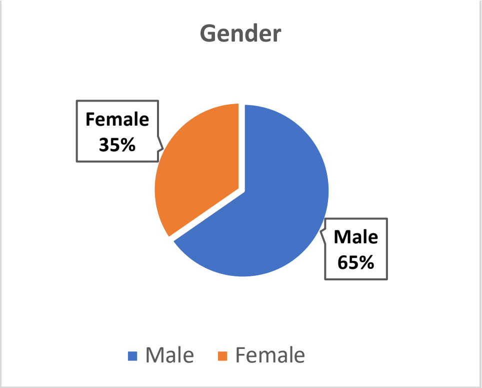
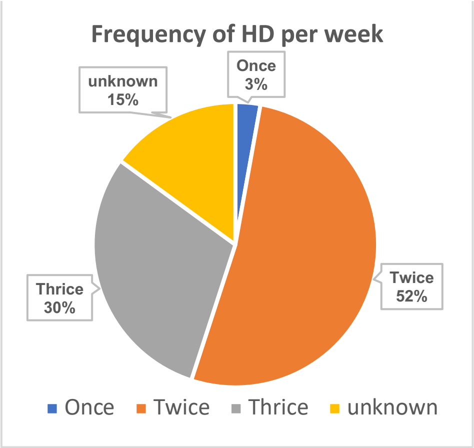


Figure 2: Frequency of hemodialysis per week among 990 PKRDS registry patients.

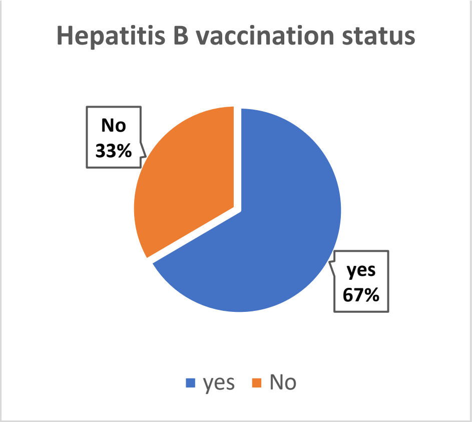


Discussion:

PKRDS has provided a wealth of data in terms of characteristics of dialysis patients. This data is far short than the actual number of dialysis patients. It has been an ongoing struggle to bring along the nephrology community to participate in this cause since it is a voluntary submission to the electronic registry.

In USA coverage of ESKD patients has since been covered from 1978 for dialysis and transplant by the governmental department of Medicare and ESKD program.[8] It mandates the health providing organizations to submit detailed data of the ESKD patients and its timely follow ups for reimbursements. This mandatory data submission has made it possible for the USRDS to incorporate this information in their registry. Thus, the success story of USRDS has been mainly possible due to this compulsion and understanding at the level of policy makers.[7]

Figure 3: Hepatitis B vaccination status among 990 PKRDS registry patients.



Some salient features of PKRDS are worth mentioning. Majority of the patients presented in PKRDS are young with a mean age of 46.6±15.2 years as evident in previous publications. Gender difference evident in the PKRDS may suggest that there is gender bias in terms of provision of health care especially the opportunity for renal replacement therapy. Diabetes Mellitus and hypertension are the main leading causes of ESKD similar to other registries.[6,10]

It is reassuring that most of the patients are being dialyzed through vascular access or graft. It is alarming to see that still 44% of patients are HCV positive, but we hope that with the introduction of HCV direct acting anti-viral therapy will change the scenario in the future. Still, at the same time we need to review our infection control policies that cause seroconversion in a lot of patients starting dialysis.[11]

It is an eye opener that 33% of the patients have not received the Hepatitis B vaccination status, which is a potentially preventable disease. The registry data highlights the areas where more stress is needed in terms of information to the patients and physicians taking care of these patients.

An active involvement of both stake holders with the right information provided will ensure future improvements in health care. When we will reach the benchmark of 5000 patients all data will be available for the investigators to look at in more detail at no cost.

Here we would like to acknowledge Professor Dr Ali Jafar Naqvi to have maintained the renal registry for many years, last published dialysis registry available for 2014.[12] His efforts and guidance has been instrumental all these years and we believe that our effort is a continuation of Dr Naqvi's efforts and we have evolved it into an electronic data base to make it possible for all the dialysis centers to contribute.

Conclusion:

In conclusion, PKRDS is the right step in the right direction. It is now the duty of nephrologists and health policy makers to support PKRDS in achieving its goals and only then we will able to see the true picture of prevailing ESKD patients.

Conflict of Interest: None declared

References

1. Metzger J. Using Computerized Registries in Chronic Disease Care. Oakland, Calif: California Healthcare Foundation; 2004.
2. Wagner EH, Austin BT, Davis C, Hindmarsh M, Schaefer J, Bonomi A. Improving chronic illness care: translating evidence into action. Health Affairs. 2001;20:64–78.
3. Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness. The Chronic Care Model, Part 2. JAMA. 2002;288:1909–14.
4. Schmittdiel S, Bodenheimer T, Solomon NA, Gillies RR, Shortell SM. The Prevalence and Use of Chronic Disease Registries in Physician Organizations. A National Survey . J Gen Intern Med 2005; 20:855–858.
5. Epping-Jordan JE, Pruitt SD, Bengoa R, Wagner EH. Improving the quality of health care for chronic conditions. Qual Saf Health Care 2004;13:299–305.
6. United State Renal Data System: Annual report. https://adr.usrds.org/2020/. Last accessed on December 10, 2020.
7. Port FK and Held PJ The US Renal Data System at 30 Years: A Historical Perspective. Am J Kidney Dis 2019;73(4):459-461
8. Eggers PW. Medicare's End Stage Renal Disease Program. Health Care Finance Rev. 2000 Fall; 22(1): 55–60.
9. Anees M, Ahmad S, Raja KM, Mushtaq M, Ibrahim M. Anemia and Mineral Bone Disorders in Patients with End Stage Renal Disease on Maintenance Hemodialysis. Pak J Kidney Dis 2020;(11): 209-213
10. The UK Renal Registry: 22nd Annual report 2018. https://renal.org/audit-research Last accessed on December 10, 2020.
11. Hussain Y, Sabir A, Naz S, Munawar N, Anjum R. Acquiring Hepatitis-C Viral Infection during Maintenance Hemodialysis Patients at DHQ Hospital Sheikhupura: A Cross Sectional Study. Pak J Kidney Dis 2020(4);2:240-244.
12. https://kidneyfoundation.net.pk/about.html. Last accessed on 2 December, 2020.