From the Desk of Editor in Chief

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A Word about Pakistan Renal Registry

The current issue will be publishing Annual report for Pakistan Renal Registry, which was compiled by Pakistan Society of Nephrology (PSN) designated body, members for which were agreed during last Executive Committee meeting of PSN.[1]

While having a nationally representative renal registry carries a great significance in the sense that a well-structured registry can facilitate better healthcare planning, improve patient outcomes, and support research initiatives aimed at understanding the renal diseases. There arises a need to highlight some points.

Firstly; It's crucial to clarify the methodology used in collecting and reporting renal registry data. As there remain a high level of debate and concerns about the methodology used in collecting and reporting renal registry data. If the data does not represent the entire country, it could lead to skewed findings that may not accurately reflect the renal health landscape in the country and might be misleading due to its country – wide representation. To further emphasize on statement above, if we have a look on current renal registry in its Figure 5 where it depicts Ethnicity of people suffering from kidney diseases major representation from Punjabi and Pakhtoon, very low Sindhi and almost negligible Balochi population, meaning that data collection was more robust from Province of Punjab and Khyber Pakhtunkhwa while Sindh and Baluchistan have not contributed much to renal registry. Whatever had remained the reasons, but unfortunately it has impacted the whole data authenticity in terms of representation at country level. Likewise, Table 2 of report which gives insights for disease pattern, among 2,155 registered patients only 5 were acute kidney injury (AKI) patients, this is highly controversial if we see a study published from country where a single center in province of Sindh reports 5,623 AKI patients dealt over a span of 25 years, similarly other centers from an interior city of Sindh reported 294 AKI patients in 7 years and a single center from Baluchistan reported 267 AKI patients in 2 years.[2-4]

There also seems a discrepancy in current registry, in number of renal calculous disease contributing to CKD only 7 of 2,155 (0.32%) registered patients reported as having kidney stones, from previously published reports from Pakistan where it was contributing 7.2 % of CKD.[5]

Another point of concern is about acknowledging the groundwork laid by other teams in the field of renal health data collection. Highlighting previous studies and registries not only gives credit to those efforts but also provides context. It could help in understanding trends over time and the evolution of renal care within the country. One registry published back in 2014 under supervision of Late prof AJ Naqvi from platform of kidney foundation and data of dialysis registry patients from all over Pakistan (claimed to be).[6] Then PKRDS publishes periodically in different issues of the same journal by Prof Waqar Ahmed, latest in September 2024 having data of 7084 patients.[7] However, both of mentioned registries were unable to cover data from all over the country and thus none can be claimed as country representative.

Recommendations to further improve the data collection would be understanding the importance of national registry and ample collaborative efforts, keeping aside all differences, carrying out detailed and repeated discussions with centers who still have reservations about contributing with data. Policy about data sharing should be clear to all and in accordance with international ethical guidelines of data sharing. All major centers from all provinces of country should join hands to make national registry more meaningful and country representative.

References:

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2. Naqvi R. Epidemiological trends in community acquired acute Kidney Injury in Pakistan: 25 years Experience from a Tertiary Care Renal Unit. Pak J Med Sci. 2021;37(2):312-9.
3. Shaikh Q, Shaikh N, Soomro A, Shaikh G, Shaikh A. Acute Renal Failure: An Experience at Nephro-Urology Department Chandka Medical College Hospital Larkana. Professional Med J. 2008;15(02):229-33.
4. Zarkoon A, Rind H, Khan M, Ahmed A, Jakrani N, Hussain M et al. Etiology and Outcomes of Acute Kidney Injury in Patients Admitted to a Single Tertiary Care Hospital: Balochistan Institute of Nephrology-Urology Quetta. Pak J Kidney Dis. 2021;4(4):319-23.
5. Rizvi SAH; Manzoor K. Causes of Chronic Renal Failure in Pakistan.A Single Large Center Experience. Saudi Journal of Kidney Diseases and Transplantation. 2002, 13(3):376-9.
6. Dialysis Registry of Pakistan.2014 http://www.kidneyfoundation.net.pk
7. Tahir S, Ahmad W. Pakistan Renal Data System (PKRDS), September 2024. Pak J Kidney Dis 2024:8(3):11-15.