

The Need for a Liver Transplant Registry in Pakistan

Sir,

The incorporation of Information Technology (IT) in healthcare data has revolutionised medical research. Only a few medical fields in Pakistan have successfully adopted IT and have made their registries, *i.e.*, Pakistan National Joint Registry and Karachi Cancer Registry.¹ Pakistan bears a major burden of liver diseases, and currently, several centres offer liver transplant services. In 2003, the first liver transplant procedure in Pakistan's history was successfully performed.² After a gap of eight years, in 2011, a local team did a deceased donor liver transplant procedure.³ From 2012 onward, several centres undertook the challenge of establishing liver transplant programs across the country. These programs started slowly but they grew over time. Due to cultural and religious restrictions, only living donor programs flourished in Pakistan.⁴

National Transplant registries are lacking in developing countries.⁵ The living donor liver transplant procedures performed last year in Pakistan are around 500. This figure is only based on rough estimates as there is no available central repository in Pakistan that gathers liver transplant-related data. The lack of exact statistics makes it challenging to calculate the liver disease burden and the required need for transplant procedures. Due to newly established liver transplant centres and the increasing number of liver transplant procedures being performed in the country, there is a serious need of establishing a liver transplantation registry in Pakistan, like established transplant registries of the United States, United Kingdom, and Australia.⁵

The national liver transplant registry will gather and analyse various transplant centres' prospective data across the country on a routine basis with web-based technology. This data will include the record of the total number of transplant procedures performed annually, recipients' and donors' demographics, immunosuppressive protocols used by various centres, short-term and long-term complications, and graft/patient survival. Establishing this registry is of utmost importance to improve the standards of liver transplant-related care at a national level. Also, this will provide the facility of analysing large data sets for impactful research work.⁶

The limited reliance on IT use and the current trend of manual data entry are the major hurdles to the development of a liver transplant registry in the country. These badly affect the data quality and are also the major reasons for missing important information. Maintaining records in hard form is also difficult

and time-consuming. A user-friendly secure robust software system will be needed for this purpose.

We believe that collective efforts by the transplant community are needed to build a national liver transplant registry for centralizing the data and improving the quality of care. Also, government authorities are requested to make efforts and to step forward in establishing the liver transplant registry.

COMPETING INTEREST:

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AW: Revision and final approval.

KU: Concept, drafting, and manuscript writing.

AM: Drafting and literature review.

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