KIDNEY TRANSPLANTATION REGISTRY PROGRAM IN MASHHAD UNIVERSITY OF MEDICAL SCIENCES: DESIGN AND RATIONALE

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ABSTRACT

Introduction: The kidney transplant registry in Mashhad, Khorasan Razavi, started in 2016. Kidney transplantation began here 20 years ago. In recent years, about 160 kidney transplantations have been performed here annually, that consisted of both cadaveric and living donor programs. As transplant outcomes have not been systematically monitored, we try to analyze and share kidney transplant outcomes performed in this center by registration of this group of patients, living donors and recipients.

Methods: This registry is a prospective, single center, longitudinal program, designed as a dynamic observational cohort which enrolls all transplant recipients. Demographic data, etiology of chronic kidney disease, and patient and graft survival were analyzed. The features of the registry are a flexible patient-case system that allows capturing all kidney transplant scenarios and collection of patient-specific and allograft-specific data. The system uses detailed basic data questionnaires in combination with follow-up visits. The dataset is designed and established using a two-round Delphi method in two versions (minimum and extended), followed by a detailed data dictionary. Every decision has been made by a group of panelists specialized in nephrology and urology.

Results: Baseline characteristics, treatment data, patient and donor condition before and after surgery, potential clinical events including hospitalization, comorbidities and graft failure are all collected. Follow-up visits have been done in the 1st and 3rd month and every year after operation. Data quality is ensured by automatic software validation and a manual data review process. The advantages of this system are the ease of input, adequacy of the data, and rapid statistical processing.

Conclusion: The registration system improves the quality of care, transplant outcomes, and identifies the risk factors of graft failure in our region. Overall, it helps to achieve a better quality of life for both living donors and recipients.

KEYWORDS: Kidney, Transplantation, Registry, Design, Outcome