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Renal transplantation in adult patients with severe learning disabilities: Experience from a tertiary renal transplant center

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People with severe learning disabilities (LD) are more likely than the general population to have major health problems due to genetic syndromes, chromosomal abnormalities or congenital anomalies of the urinary tract causing chronic kidney disease. Patients with LD often face significant barriers to accessing medical treatment and lifesaving treatment such as transplantation. People with LD are more vulnerable in acute hospital settings and at greater risk of adverse incidents compared to the general population. Recent studies indicate 6-8.5% of adults in England have stage 3-5 chronic kidney disease (CKD). The prevalence of renal replacement therapies in England has grown by almost 50% over the last decade. Not everyone is a candidate for kidney transplantation due to conditions surrounding their quality of life. LD is an example in which it might be better for the patient to remain on dialysis as opposed to transplantation if they have issues with medication compliance. Renal transplantation in patients with LD raises a number of questions both clinically and ethically, such as potentially diverting scarce resources and donor kidneys away from patients with normal mental ability. The challenging experiences encountered by patients with LD at this unit led to the development and implementation of a formal individualized admission care plan, in advance of transplantation in order to provide, safe, high quality care without compromising patient safety. This study focused on the challenges posed pre dialysis, pre transplant, on admission, post operatively and the importance of the multidisciplinary team in creating an individualized patient centered approach along with successes of all those transplanted.

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