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Exploring patient, family and clinician perspectives about the psychosocial factors influencing access to kidney transplantation and transplant outcomes for children

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Objectives : We undertook a multi-centre qualitative study that explored the range of psychological and social factors that children, their carers and their paediatric nephrology multi-disciplinary team (MDT) perceived to influence how soon a child with stage 5 Chronic Kidney Disease accesses a kidney transplant. This included factors that were perceived to influence kidney transplantation outcomes or deemed important to patients and their families in terms of their quality of life.

Methods : Semi-structured interviews were conducted with CYP, their carers and their paediatric nephrology MDT across 8 tertiary paediatric nephrology units in the United Kingdom. These interviews were reviewed for pertinent themes using thematic Analysis following the approach of Braun and Clarke.

Results : A total of 37 interviews were conducted with 13 families and 18 members of the paediatric nephrology MDT. The majority of participating families identified as White (57%), followed by Black (22%) or Asian (21%). The following themes were deemed important to accessing kidney transplantation and post-transplant outcomes: health beliefs; relationship with and trust in healthcare; support networks; family relationships; socioeconomic circumstances; culture and race; and mental health and coping strategies. Some of these factors influenced how clinicians, CYP or their family viewed the CYP as a suitable transplant candidate. Other factors influenced why families opted for living or deceased donation. Specific challenges from living with CKD5 and living through the COVID-19 pandemic were also discussed due to their impact on QoL and accessing a kidney transplant

Conclusions : There are a wide range of psychosocial factors that are perceived to influence a CYP's access to kidney transplantation. Longitudinal and prospective studies are needed to fully assess the relationship between these psychosocial factors and a CYP's access to, and outcomes of, kidney transplantation.