

Barriers to kidney transplantation in children – ATTOMIC prospective national study

Dr Matko Marlais^{1,2,3}, Dr Ramnath Balasubramanian², Dr Mordi Muorah⁴, Dr Carol Inward⁵, Dr Graham Smith⁶, Dr Ben Reynolds⁷, Dr Pallavi Yadav⁸, Dr Henry Morgan⁹, Dr Mohan Shenoy¹⁰, Dr Yincen Tse¹¹, Dr Farida Hussain¹², Ms Sarah Grylls¹³, Dr Manish Sinha³, **Dr Stephen Marks^{1,2}**

¹UCL Great Ormond Street Institute Of Child Health, London, United Kingdom, ²Great Ormond Street Hospital for Children NHS Foundation Trust, London, United Kingdom, ³Evelina London Children's Hospital, London, London, United Kingdom, ⁴Birmingham Children's Hospital, Birmingham, United Kingdom, ⁵Bristol Royal Hospital for Children, Bristol, United Kingdom, ⁶Children's Hospital for Wales, Cardiff, United Kingdom, ⁷Royal Hospital for Children, Glasgow, United Kingdom, ⁸Leeds Children's Hospital, Leeds, United Kingdom, ⁹Alder Hey Children's Hospital, Liverpool, United Kingdom, ¹⁰Royal Manchester Children's Hospital, Manchester, United Kingdom, ¹¹Great North Children's Hospital, Newcastle, United Kingdom, ¹²Nottingham Children's Hospital, Nottingham, United Kingdom, ¹³Southampton Children's Hospital, Southampton, United Kingdom

INTRODUCTION

Pre-emptive living donor renal transplantation is widely accepted as the gold standard treatment for children with end-stage kidney disease (ESKD). Despite this, many children spend years on dialysis before proceeding to transplantation. However, the reasons for this are not well documented in the literature. The aim of this study was to investigate access to paediatric renal transplantation and potential barriers within the process.

METHODS

This was a prospective multi-centre observational study on behalf of the British Association for Paediatric Nephrology where paediatric nephrology centres in the United Kingdom (UK) were asked to provide data on all children (aged <18 years) with ESKD (defined as an estimated glomerular filtration rate $\leq 15 \text{mls/min/1.73m}^2$). Data collected included (where relevant) current renal replacement therapy, future transplantation plans with stage of living donor work-up and deceased donor listing. In those where transplantation was not planned or delayed, barriers to transplantation and estimated timescales were documented.

RESULTS

308 children with ESKD were included in this study from 12 out of 13 paediatric nephrology centres in the UK. 180 (58%) children were on dialysis, 37 (12%) were transplanted (Stage V(T)-CKD) and 91 (30%) children had ESKD but were currently pre-dialysis. 139 (45%) were currently being worked up for a living donor transplant, 82 (27%) children were listed for a deceased donor transplant, 22 (7%) children were both being worked up for a living donor transplant and listed for a deceased donor transplant. The mean estimated time to transplant in those with active plans was 13.6 months. 226 (73%) children were not being planned for a pre-emptive transplant or were already on dialysis. The commonest reasons for children not having a pre-emptive transplant were that the child presented in ESKD (31%), lack of a suitable donor (27%) or being too young for transplant at the time of needing renal replacement therapy (24%). High HLA sensitisation was listed as a reason in 9% of children.

The commonest cited factors preventing transplantation from occurring in children were disease factors (36%), donor availability (27%) and size of the child (20%). Patient psycho-social factors were listed as a barrier in 19% of children.

CONCLUSIONS

In this study we have documented the main barriers to renal transplantation in children. Some factors identified may be potentially modifiable through local or national intervention and include donor availability and patient psycho-social factors. A further national prospective study is planned to evaluate potential modifiable barriers to transplantation and to determine how best to ameliorate them. Improving access to renal transplantation for children will reduce the proportion of children requiring dialysis and in turn reduce the associated mortality and morbidity.