

Title of Paper: The Sibling Voice – The Experience of Kidney Transplantation from the sibling perspective

Author(s): Walsh GM, Metcalfe A, Gallagher K, Gill C, McCulloch MI.

Institution: Evelina London Children's Hospital, Kings College London, Red Cross War Memorial Children's Hospital, Cape Town.

Abstract:

Introduction: The sibling relationship is one of the most significant of our lifetime, the longevity frequently surpassing the parent-child relationship and yet renal health professionals have performed limited research surrounding the sibling experience. This paper presents a study which explored the sibling experience of living within a family where one child is a kidney transplant recipient. This study gave a voice to these children, often invisible to transplant teams, whose usual focus is the sick child and their parents.

Objectives: The key objective was to explore the sibling's individual experience of living alongside their brother/sister's transplant journey. Simultaneously, the siblings were asked whether they felt their information and support needs were met. The results would determine if a need existed which required the development of a sibling intervention.

Methods: This qualitative study was cross-sectional in design and used a phenomenological approach. Data collection was by means of individual interviews. Thematic analysis was performed on the data.

Results: 10 siblings, aged 10-17 years whose brother/sister had received a kidney transplant (either live or deceased donor) at one transplant centre participated.

5 Key themes emerged from the data as follows:-

Theme 1 'We're your child too' about parental attention

Theme 2 'We need to know' about the sibling need for information

Theme 3 demonstrated 'maturity beyond their years'

Theme 4 related to the sibling's protectiveness, the invisible bond of siblingship

Theme 5 related to enrichment of their lives

There was an acknowledgement of differential parental attention between their sick brother/sister and themselves. For some this was a problem, but many acknowledged the difficult time their parents experienced, displaying a maturity beyond their chronological years. There was evidence of protectiveness toward their brothers/sisters.

Findings showed siblings were keen to be kept informed about their sibling's transplant journey whilst the participants considered support opportunities to be important, although the majority did not want this to be a compulsory component of care.

Conclusions:

As a result of these research findings, a sibling survey is being planned within our transplant unit to explore what type of support the siblings would like to see developed.

Name of presenting Author(s): Grainne Walsh

Profession of presenting Author (s): Transplant Clinical Nurse Specialist