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RCPCH abstracts

G78 FATHERS AND MOTHERS OF CHILDREN WITH LONG-TERM KIDNEY CONDITIONS: A QUALITATIVE STUDY OF THEIR CONTRIBUTIONS TO THEIR CHILD'S HEALTHCARE

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Objectives: Parents are expected to contribute to the expert/ medical management of chronic disease in their children in many ways, including medication administration, feeding regimens, injections and home dialysis at the same time as being "normal" parents. Their involvement is well documented to be very important and the quality of it may affect the clinical outcome. Since previous research has focussed on mothers as the main respondents, fathers' views are underrepresented. Our objective was to explore/compare parents' individual and joint accounts of their contributions to care.

Methods: As this was a previously unexplored area of clinical practice, a qualitative design based on the principles of grounded theory was used. Parents were selected from one UK children's kidney unit using a purposive sampling approach based on their child's age, gender and level of clinical intervention needed. Mothers and fathers of 59 children each received postal invitations to participate. Confidentiality and anonymity were assured. The resulting sample involved 14 couples (the parents of 15 children with a long-term kidney condition) who represented a range of educational backgrounds, social circumstances and occupations. Data were obtained through 28 individual and 14 joint, semistructured interviews, tape-recorded/transcribed/analysed using a process of constant comparison. Individual and joint datasets were compared and contrasted.

Results: Parents generally shared the management role but had different ways of coping with this. Analysis revealed five themes that we called: Developing skills; Impact of the condition on daily life; Mutual support; Coping and Things that help. Emotional/ physiological effects were reported by some when managing care at home (even parents who were health professionals). Fathers sometimes coped by "disengaging" from the situation, they needed to understand the "bigger picture", what might happen in the future and be reassured that professionals "know what they are doing". Mothers' coping was facilitated by remaining close to the situation. They were more likely to consider the impact on family life and how they could adapt to it.

Conclusions: Although fathers' and mothers' healthcare roles are similar, they may deal differently with the consequences, and their emotional and practical support requirements may need to be addressed differently.