

FATHERS AND MOTHERS OF CHILDREN WITH LONG-TERM KIDNEY CONDITIONS: PARENTAL ROLES IN MANAGING THE CONDITION

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BACKGROUND: The role of fathers in managing chronic childhood illness has only recently been recognised in the research literature and kidney conditions are particularly under-represented. Mothers' views have frequently been used as a proxy for fathers' in research claiming to report parents' views, even though both parents often play a part in the sometimes complex home-based-management of these conditions.

Methods: This study, therefore, aimed to:

- determine the separate and joint views of mothers and fathers on their own and their partners' roles in managing their child's long-term kidney condition following referral to a children's kidney unit
- compare mothers' and fathers' individual and joint reported views.
- contribute to the practice and academic knowledge bases about mothers' and fathers'-roles in management of long-term kidney conditions.

Approval was obtained from the University Research Ethics Committee (REC), the Local REC, the R&D Department and the Caldicott Guardian in the NHS Trust before commencing the study. Because this is a previously under-explored area we used qualitative methods within a grounded theory approach. Mothers and fathers of 59 children previously diagnosed with a long-term kidney condition were identified from the patient database in a regional children's kidney unit using a sampling matrix based on:

- level of home-based clinical management required by parents
- the child's age and gender

Both parents were invited to take part in individual, semi-structured research interviews followed by joint, semi-structured interviews at a time/date/place convenient to them. Mothers and fathers each received postal invitations to participate. Confidentiality and anonymity were assured. Sixteen couples expressed interest; however, two couples no longer met the inclusion criteria, therefore, 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, semi-structured interviews that were conducted in parents' homes or workplaces. Interviews were tape-recorded and transcribed before being analysed using a process of constant comparison. Systematic data management was supported by Framework Technique. Individual and joint data sets were compared and contrasted.

RESULTS: Analysis revealed five themes: 1-Developing skills; 2- Impact of the condition on daily life; 3-Mutual Support; 4-Coping, and 5-Things that help. Emotional and physiological effects were reported by some parents when managing clinical care at home (including those who were health professionals). Fathers sometimes managed by 'disengaging' from the situation, they needed to understand the 'bigger picture', what might happen in the future and be reassured that professionals 'knew what they are doing'. Mothers' involvement was facilitated by remaining close to the situation and they were more likely than fathers to consider the impact of the condition on family life and how they could adapt to it.

CONCLUSIONS: Although fathers' and mothers' care-giving roles are similar, they often deal differently with the consequences. Fathers' involvement is, therefore, an important target for interventions that promote family's home-based management competence. Further research is needed to investigate these differences in a larger sample of parents, using reliable/valid measures.

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