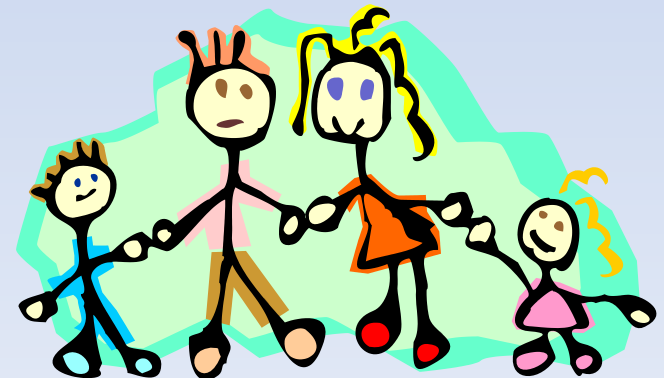


Families learning to manage home-based care-giving for long-term kidney conditions early in the trajectory: qualitative accounts

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...parents may perform the vast majority of care-giving, including tasks that are complex and demanding (DOH 2006:14)

Reference:

DOH. National Service Framework for Renal Services: Working for Children and Young People. London 2006.

DoH/DfES. Every Child Matters-National Service Framework for Children, Young People and Maternity Services. Nottingham: Department for Education and Skills 2004.

Table 1: Relationship between levels of intervention, chronic conditions and skills/competencies required by families

Level of intervention	Typical conditions	Skills/competencies required by families
Low intervention ↓ ↓ → ↓	↓ ↓ Vesicoureteric reflux	→ Communication with professionals → Urine collection → Negotiating urinalysis with GP surgery → Administration of antibiotics → Taking temperature → attending inpatient/outpatient appointments
Moderate intervention ↓ ↓ ∞	↓ ↓ Steroid Sensitive Nephrotic Syndrome	→ Communication with professionals → Obtaining/testing urine for protein → Monitoring fluid intake → Monitoring weight → Monitoring diet → Administration of medications → attending inpatient/outpatient appointments
High intervention ↓ ↓ ↓ ↓ ↓ ∞	↓ ↓ End-Stage Renal Failure	↓ ↓ → Communication with professionals → Home-based → Management of peritoneal dialysis, urine collection and urinalysis, administration of growth hormone or erythropoietin injections, intravenous therapy and oral medications → monitoring diet and weight → attending inpatient/outpatient appointments

Methods

Data collection

- 47 semi-structured interviews with children/parents
- 22 post-interview case-note reviews
- 4 family learning diaries

Data analysis

- Framework Analysis



Dependent learning

- attention to detail
- lack of understanding
- inconsistency in skills

Dependent learning

At first, I had trouble grasping what the doctor was saying about Carol's illness, we'd not had much to do with hospitals, I felt I only really understood the surface information...

[father] took this [discharge letter to GP that was copied to parents] to the pub, his friend tried to explain what it all meant...then me Dad went on the internet for information

The nurses are good, show us things in stages, one stage at a time so that we learn it [how to pass a naso-gastric tube] or set up the iv more easily...they write it down here [record]

Co-dependent learning



- **less attention to detail**
- **developing anticipation about changes**
- **anticipating changes**

Co-dependent learning

Kate: ... the nurse comes round with the doctors and after that round I'm not always sure what they meant, plus nurses are more trained, clearer about reading the notes, nurses can chat to you and say 'right, this is what we think it is'... even "we're not 100% sure but will find out for you"

Interviewer: Almost like a go-between to start with?

Kate: Well, yes, they are friends as well

Every time I go [to the clinic], they ask me what medication he's on and that...well I mean I'm his mother not a nurse. They should know and not be asking me



Independent learning

- **competently adjust management**
- **performance gains slower**
- **increasingly empowered**

Independent learning

I realise now if she's goes pale and sunken eyed and is off her food I need to get her to hospital...at one time I would have asked my Mum to look at her, then rang the GP. I'd probably have struggled to get an appointment and then have gone to A&E at the local hospital, now I know it means she's probably dehydrated, ring the unit and say I'm bringing her in-I don't mess about

Independent learning

When I first went home, I used to talk aloud to myself while doing it and repeat what the nurses had said when showing me, just because it helped me visualise what I was doing and gave me more confidence. Now though I can do it without thinking-well almost !!



Conclusions

- **Family learning is an important (but previously unexplored) aspect of management**
- **Early interventions to promote family competence may be enhanced by these insights into family learning.**
- **Support building on these factors is more likely to:**
 - **be tailored to families' learning needs**
 - **enhance competence development**
 - **optimise children's clinical outcomes**

Reference: Swallow V, Lambert H, Clarke C, Campbell S, Jacoby A. Childhood chronic-kidney-disease: A longitudinal-qualitative study of families learning to share management early in the trajectory. Patient Educ Couns. 2008;73:354-62 Online

Our current research:

Teaching parents to become home-based care-givers of children's long-term kidney conditions: a mixed methods study in all Children's Kidney Units in Great Britain

Funded by Kids Kidney Research UK

Adopted by Medicines for Children Research Network (MCRN)

Research team: Swallow V, Webb N, Lambert H, Smith T, Williams J, Allen D, Boxshall L, Crosier J, Wirz L, Rogers C