

Collaborating to develop an online resource for parents

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Participants in a National Institute of Health Research-funded project reflect on the collaborative process of developing an online resource for parents of children with a long-term condition

Background

The development and evaluation of Online Parent Information and Support (OPIS) involved the creation of a web resource for parents who needed support for the home-based management of their child's chronic kidney disease (CKD).

Methods

Qualitative interviews with parents, patients and professionals were undertaken to explore their views on the desired content of the OPIS website. OPIS was then developed and tested by 84 parents of children with CKD in a feasibility randomised controlled trial (Carolan et al 2014, Swallow et al 2014a, 2014b, Huby et al 2016, Swallow et al 2016).

Findings

Parents who had access to the online support during the trial showed a greater improvement in perceived competence to manage their children's condition. It has since become standard practice at the authors' hospital to give parents access to the online resource.

Lessons learned

The project was funded by The National Institute of Health Research, and involved a clinically based nurse with protected and funded research time. This was essential to demonstrate the importance of the project to the multidisciplinary team and to reassure families involved in the studies.

Paediatric renal nurse specialist Trish Smith was involved in the recruitment, and she co-ordinated the training of a researcher to recruit parents and collect and analyse data. The researcher was not a health professional so the training included periods of shadowing clinical staff, education in renal treatments and meeting families. The nurse specialist introduced the researcher to the families, which increased their confidence in the research process and enhanced recruitment. The nurse specialist's involvement provided a good collaboration point between the university and the tertiary children's hospital that collaborated on the project. Local knowledge of the clinical area, and good rapport with children and families, were vital to the success of the study.

Listening to the views of parents and involving them in the research design were crucial to the success of this project. Two parents whose children had CKD and had experienced renal replacement treatment over several years were integral to the project.

Implications for practice

This study demonstrates that it is possible to co-produce, evaluate and put into practice a rigorously developed resource to support families living with long-term conditions. Paediatric nurses should be fully involved in research projects from their inception, and should be given protected time and funding. They are pivotal in bridging the gap

between researchers and participants, provide a valuable link with families, and can promote and endorse the project in the clinical environment.

A parent who participated in the study commented: 'It is essential we have a website such as OPIS. It is so valuable to our state of mind, and helps maintain a level of security and confidence in our home care. It also expands to other people associated with our children's care, such as school staff. It is a fast, efficient and factual way to gain knowledge on our children's condition.'

This research project has shown that children and young people's nurses are well placed to drive research forward, helping to deal with the difficulties encountered during collaborative working. Partnership is vital to getting research established and transferring findings into practice. Sharing these research opportunities with families enables greater collaboration.

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All for and on behalf of RCNs Research in Child Health community