

A qualitative exploration of parental experiences of introducing and implementing Clean Intermittent Catheterisation on two - four-year-old sensate children.

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Introduction:

There is currently a lack of research describing the lived experiences of parents (and carers) who utilise Clean Intermittent Catheterisation (CIC) as a long term management for their child's bladder condition, throughout their journey from the point of diagnosis to initial introduction of this treatment to their child and longer-term management of their child's bladder condition. Our study aimed to understand the lived experience of parents across emotional, practical and social dimensions and how these experiences might change over time.

We were specifically interested in focussing our study on young children who are considered to have normal urethral sensations, as research has indicated that although introducing CIC to sensate infants can be successful, difficulties with CIC are more present for parents of young children (over 2 years of age) who are sensate as the procedure may cause the child pain and distress (Pohl, 2002; Bowmers et al, 1996). This finding has resonated with our own team's clinical observations and reported clinical outcomes, where greater challenges in acceptability for parents and success in implementation have been evident in families of young children, between two and four years old. We used qualitative research techniques to learn from parents about their challenges and strategies for overcoming difficulties to help inform our practice and improve both experience and clinical outcomes for future families.

Methods:

Eight parents took part in semi-structured interviews about their experiences of learning of their child's diagnosis and need for catheterisation, being trained to use CIC and implementing it at home with their child. All interviews were transcribed and a systematic method of Thematic Analysis (Braun and Clarke, 2004) was used to generate themes and sub-themes about parents' experiences.

Results:

Three key themes were identified reflecting three significant aspects of parental experience: 1) Encountering difficulties, 2) Establishing confidence, and 3) Perceived support. All parents encountered some level of psychological, procedural or logistical difficulties learning and/or implementing CIC on their child. The majority of parents managed to establish confidence in doing CIC on their children. Internal factors such as parental acceptance of CIC, experiential learning, planning, and routines, were all expressed by parents as being important in helping them establishing confidence with CIC. Furthermore, the external support parents perceived receiving (across the sub-themes emotional, practical and social support) was expressed by parents as influencing their experiences of introducing and implementing CIC on their child.

Discussion:

Our findings reveal important implications for how service providers could ensure parents feel as supported as possible during the CIC treatment pathway. For instance, in our institution, we have discussed the following three suggestions. Firstly it could be encouraged that both parents are taught CIC, to decrease the burden on one parent. Secondly, greater emotional support for parents should be available such as a

psychologist or a counsellor. Finally, medical services should create and promote opportunities for parents who are catheterising young children to meet and support each other.