

On parental self-efficacy in families with paediatric cataract and its clinical implications

Akademisk avhandling

Som för avläggande av medicine doktorsexamen vid Sahlgrenska akademien, Göteborgs universitet kommer att offentligens försvaras i 2403 Gösta Sandels, Academicum, Medicinaregatan 9B, Göteborg, fredagen den 20 november klockan 09.00

av JENNY GYLLÉN

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Avhandlingen baseras på följande delarbeten

- I. Gyllén J, Rosenberg A, Nyström A, Forsberg A, Magnusson G. *Important sources of information on self-management for families of children with pediatric cataracts – based on PECARE Sweden/Sahlgrenska University Hospital*. International Journal of Ophthalmic Practice. 2015 Feb/March:23-29
- II. Gyllén J, Magnusson G, Forsberg A. *Uncertainty and self-efficacy in parents of a child with congenital cataract—New implications for clinical practice*. Nursing Open, 6(3), 799-807
- III. Gyllén J, Magnusson G, Forsberg A. *The Core of Parents' Main Concerns When Having a Child With Cataract and Its Clinical Implications*. Journal of Pediatric Nursing. 2019; 44, e45-e51
- IV. Gyllén J, Magnusson G, Forsberg A. *Parents' reported experiences when having a child with cataract - important aspects of self-management obtained from the Pediatric Cataract Register (PECARE)*. International Journal of Environmental Research and Public Health 2020, 17, 6329

**SAHLGRENKA AKADEMIN
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Abstract

Introduction: Parent participation is implicit in all paediatric care. Responsibility for the treatment after cataract surgery (contact lenses, patching, eye drops and being alert to signs of complications) mainly lies with parents. However, little is known about what parents go through and what kind of support they need from the ophthalmological team.

Aims: To understand (I-III), explore (I and IV) and explain (IV) self-efficacy among parents of a child with paediatric cataract in order to promote self-management and improve clinical care.

Patients and methods: Study I: questionnaires with open and closed questions were sent to parents of children (n=72) registered in the PECARE (Paediatric cataract register) and to paediatric ophthalmologists (n=30). In studies II and III, in-depth interviews with 23 parents were analysed using directed content analysis (II) and the grounded theory method (III). In Study IV, questionnaires were sent to all parents of children registered in the PECARE since 2006 (n=506). Four scales were selected: sense of coherence, fatigue, perceived social support and family self-efficacy, and on patient-reported experience measures (PREM).

Results: Studies I and IV revealed what prerequisites the parents have – or do not have. In Study I, they wanted something they did not get, i.e. more information, both written and online. In Study IV, fatigue emerged as an obstacle to the sense of coherence, especially among parents of children with bilateral cataract. Studies II and III provided an in-depth understanding of the parents' self-efficacy and what strategies they use to adapt to a life in balance with a child with cataract. A model was developed in Study III to describe the parents' situation.

Conclusion: Parents go through a profound adaptation process throughout their child's visual trajectory. As they are a self-evident part of the care of their child, the team needs to acknowledge that fatigue and uncertainty constitute a barrier to self-efficacy. This could be achieved by using a digital app, introducing a key worker and including other professions to the ophthalmological team in order to implement family centred care.

Keywords: Paediatric cataract, parents, family, caregiver, self-efficacy, self-management