Growing Up with a Chronic Illness: Parents’ Perspectives

O’Sullivan, A., Wehling, H., Barnes, S. & NiMhurchadha, S.

Atlantis Healthcare, London, UK
**Objectives**

To understand parents’ experiences of raising a child with a chronic illness

To understand areas where further support is needed for parents

**Methods**

**Inclusion Criteria**
- Child (aged 4-17) with Juvenile Idiopathic Arthritis (JIA) OR Pediatric Psoriasis

**Participants**
- N=32 parents (84% female)
- [JIA parents, n=17; Psoriasis parents, n = 15]

**Procedure**
- 60 minute telephone interviews

**Data Analysis**
- Transcripts analysed using NVivo Pro 11 by two analysts using thematic analysis (Braun & Clarke, 2006)
Life as the Parent of a Child with a Chronic Illness

Key Themes

- Life changes when you have a chronically ill child
- It’s an emotional rollercoaster
- There is little support for parent or child
- Promoting normalcy in the face of stigma and isolation
- Coping through keeping calm and focusing on the future
- The parent role: from expert to observer
Implications

Interventions to support parents of children with chronic illnesses should address parents’:

- Understanding of their child’s illness and treatment to support their self-efficacy
- Confidence managing and supporting their child to manage their own condition
- Emotional wellbeing to reduce emotional burden
- Coping strategies to encourage positive coping
- Relationships and perceived social support to reduce social isolation, including:
  - Relationship with the child
  - Relationships with the child’s healthcare professionals
  - Access to similar parents and children to encourage the sharing of experiences