

Caring for children with new medical technology at home: parental perspectives

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ABSTRACT

Objectives: This qualitative descriptive study explores the experiences of family caregivers (FCs) of children with medical complexity who are initiated on new medical technology in the hospital and transition to new daily life at home. The study aims to investigate FCs' response and readiness for medical technology use, the value of education and transition support and the challenges associated with managing new medical technology in the home.

Study design: A qualitative descriptive approach was used to conduct and analyse 14 semistructured interviews with a group of FCs composed of 11 mothers and 3 fathers. Content analysis was used to analyse transcripts of the caregiver interviews. The study was conducted at a tertiary paediatric hospital in Toronto, Canada.

Results: Our study revealed three main themes: FC's response and readiness for medical technology use, the value of education and transition support for initiation of new medical technology and the challenges associated with managing new medical technology in the home. FCs expressed emotional distress related to coping with the realisation that their child required medical technology. Although the theoretical and hands-on practice training instilled confidence in families, FCs reported feeling overwhelmed when they transitioned home with new medical technology. Finally, FCs reported significant psychological, emotional and financial challenges while caring for their technology-dependent child.

Conclusions: Our study reveals the unique challenges faced by FCs who care for technology-dependent children. These findings highlight the need to implement a comprehensive education and transition programme that provides longitudinal support for all aspects of care,

INTRODUCTION

Children with medical complexity (CMC) are a growing population due to advancements in medical care and home technologies without which they would not have survived previously.^{1–3} CMC are a group of 'diagnostically heterogeneous children whom are united by multiple chronic conditions, significant functional limitations and dependence on technology'.⁴ CMC and their family caregivers (FCs) endure enormous

WHAT IS ALREADY KNOWN ON THIS TOPIC

→ Family caregivers of technology-dependent children with medical complexity experience several challenges in their transition home from hospital, especially related to medical technology complications.

WHAT THIS STUDY ADDS

→ A training programme that combines theoretical and hands-on learning can increase family caregivers' confidence in managing medical technology at home.
→ Family caregivers of children who are initiated on medical technology in hospital desire having more robust support following their discharge home as they adapt to new life.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

→ There is a critical need to develop comprehensive education programmes for family caregivers whose children are initiated on medical technology in hospital.
→ Educational and psychosocial supports should be available during the disclosure of the need for medical technology, training process, transition home and postdischarge period.

challenges, including prolonged hospitalisations, poor care coordination and caregiver burden.^{4–6} Due to their underlying medical fragility, CMC often are frequent users of the healthcare system and experience significant morbidity and mortality.^{3,7}

Families of CMC have reported that transitioning from hospital to home with technology-dependent children can be demanding because of the involvement of multiple healthcare providers and services.^{8–9} This transition experience is especially heightened by the addition of new medical technology such as tracheostomies, ventilators and feeding tubes. A substantial amount of emergency department visits and hospital encounters in CMC are related to medical

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**René Levy, Paolo Ghisletta, Jean-Marie
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The Evolution of Parental Care Nick J. Royle, Per T. Smiseth, Mathias Kölliker, 2012-08-09 Parental care includes a wide variety of traits that

enhance offspring development and survival This novel book provides a fresh perspective on the current state of the study of the evolution of parental care written by some of the top researchers in the field and taking a broad taxonomic approach

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