Parent Education Programs for Children with Medical Complexity: An Integrative Review

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Background

- Children with medical complexity (CMC) are a high needs subgroup of children with special health care needs, characterized by:
  - Family-identified service needs (e.g., medical care, specialized therapy, education)
  - Chronic condition(s) associated with medical fragility (e.g., spinal muscular atrophy, congenital heart disease, epilepsy, chronic lung disease)
  - Functional limitations (e.g., ambulation, breathing, or feeding impairments), and
  - High health care utilization (e.g., frequent or prolonged hospitalizations, multiple subspecialist providers)

- CMC represent an estimated 0.4% of children in the United States and account for 1/3 of pediatric health care spending.
- Parenting CMC is associated with unique demands and challenges:
  - Greater caregiver and economic burden
  - Increased worry, anxiety, social disruption, conflict with home care providers, and parental role conflict
  - Benefits of parent education programs for children and youth with special health care needs have been established; however, no systematic reviews have examined how parent education programs can benefit the subgroup of CMC

Search and Retrieval Process

- Inconsistencies in describing this population of children exist in the literature.
- Few parent education programs directly target parents of CMC and among those that do, the focus is on providing adequate caregiver education to support safe home care.
- Parent education programs for families of children and youth with special health care needs demonstrate a positive impact on parent-child relationships, coping skills, and family functioning.
- There is a need for continued development of evidence-based parenting education programs to meet the unique needs of parents of CMC

Results, cont.

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<td>DeMaso et al. (2000)</td>
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Conclusions

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Purpose

To systematically examine components of parent education programs for CMC and synthesize evidence about these programs' effectiveness on parent and/or child outcomes.

Methods

- Whittemore and Knafli's (2005) integrative review methodology
- Study Selection:
  - Inclusion Criteria:
    - Described an intervention focused on providing education to parent and/or family caregivers
    - Included children between 0-18 years of age
    - Child population is medically complex or can be characterized this way
    - Measured a parent and/or child outcome
  - Exclusion Criteria:
    - Full-text was unavailable electronically or in English
- Search Method:
  - Databases: Cumulative Index of Nursing and Allied Health Literature, PubMed, Scopus, and PsycINFO
  - Keywords: “children with medical complexity” AND “caretaker” AND “training”
- Data Extraction and Synthesis:
  - Study variables extracted in data collection tools developed by investigators
  - Papers reviewed and findings synthesized

Components

- Resourcefulness
- Transactional Stress and Coping Model
- Caregiver stress
- Procedure (journaling)
- Acceptability of study
- Negative emotions
- Infant feeding
- “Caregiver” AND “training”