

Children's Experiences of Cancer Care: A Systematic Review and Thematic Synthesis of Qualitative Studies

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PROBLEM IDENTIFICATION: Improvements in pediatric cancer survival have increased interest in the experiences of children undergoing treatment; however, no review of the qualitative literature describing these experiences has been conducted.

LITERATURE SEARCH: Databases were searched from January 2000 to January 2016 for qualitative studies describing the experience of children with cancer aged 18 years or younger.

DATA EVALUATION: Two reviewers assessed abstracts for relevance and rated reporting comprehensiveness. Participant quotations and descriptions of participants' comments and behaviors were coded. Coded data were pooled to provide a thematic synthesis.

SYNTHESIS: 51 studies were included. Five themes were identified: suffering because of cancer, fluctuating realities, coping strategies, new roles and responsibilities of the child, and practical resources to enable managing cancer. Children articulated physical, emotional, and social challenges and made suggestions to improve their quality of life during therapy.

IMPLICATIONS FOR RESEARCH: Results provide data related to the experience of children with cancer that can inform practice changes and research activities aimed at enhancing quality of life.

KEYWORDS cancer; pediatrics; qualitative research; systematic review; thematic synthesis

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Cancer is a leading cause of disease-related death in children and adolescents globally (Magrath et al., 2013; Siegel et al., 2014). However, the long-term survival rate of children with cancer is increasing, and the five-year survival rates across all cancer types in high-income countries exceed 80% (American Cancer Society, 2016; Hudson, Link, & Simone, 2014). Still, the burden of the disease and the intensive nature of cancer therapies are associated with acute toxicities and chronic health conditions that are often life-threatening (Hudson et al., 2013). During cancer treatment, children and adolescents with cancer experience a myriad of physical (e.g., pain, nausea, fatigue, hair loss) and psychosocial (e.g., stress, anxiety, depression, isolation) symptoms related to the disease, invasive procedures, and/or chemotherapy and radiation (Baggott et al., 2010; Dupuis et al., 2010; French et al., 2013; Zhukovsky et al., 2015). Children and adolescents with cancer are challenged to adhere to complex and often time-consuming treatment regimens, manage adverse effects, plan for the future (including transition to adult care or aftercare), and maintain a positive outlook (Zebrack & Isaacson, 2012).

Examination of the impact of cancer and its treatment from the patient's perspective has been advocated for at national levels to complement traditional, medically focused outcomes and to provide a comprehensive picture of treatment effectiveness (Dueck et al., 2015; Reeve et al., 2013; Thornton, 2008). Qualitative research can provide detailed insight into the beliefs and experiences of individuals with cancer, including children, which can be used to shape clinical care and research (Sigurdson & Woodgate, 2015). A body of qualitative literature has explored the experiences of children with