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To understand the experiences, needs, and preferences for supportive care, among children and adolescents (0–19 years) diagnosed with cancer: a systematic review of qualitative studies

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Abstract

Purpose: This study aimed to understand the experiences, needs, and preferences for supportive care, among children and adolescents (0–19 years) diagnosed with cancer.

Methods: A qualitative systematic review has been reported according to PRISMA guidelines. A comprehensive search was conducted across multiple databases (APA PsycINFO, CINAHL, and Medline) and citation searches. Studies were screened according to pre-determined inclusion and exclusion criteria. Methodological quality was evaluated. Findings were extracted in relation to the context of interest of experiences, needs, and preferences of supportive care. Each finding was accompanied by a qualitative verbatim illustration representing the participant's voice.

Results: 4449 publications were screened, and 44 studies were included. Cancer populations represented in the included studies included lymphoma, leukaemia, brain cancer, sarcomas, and neuroblastoma. Two overarching synthesised findings were identified as (1) coping, caring relationships, communication, and impact of the clinical environment, and (2) experiences of isolation, fear of the unknown, restricted information, and changing self. Children and adolescents articulated that cancer care would be enhanced by developing a sense of control over their body and healthcare, being involved in communication and shared decision-making, and ensuring the clinical environment is age-appropriate. Many experienced a sense of disconnection from the rest of the world (including peers, school, and experiences of prejudice and bullying), and a lack of tailored support and information were identified as key unmet care needs that require further intervention.

Conclusions: Children and adolescent who are diagnosed with cancer are a unique and understudied group in oncological survivorship research, with the slowest progress in improvement of care over time. This review will facilitate the development of future interventions and promote the importance of tailored support for children and adolescents at all stages of the cancer journey.

Implications for cancer survivors: Children and adolescents continue to experience a range of difficulties despite routine contact with cancer healthcare professionals. Children and adolescents should be carefully assessed about their individual circumstances and preferences for support given the clear implications from this review that "one size" does not fit all.

Keywords: Adolescents; Children; Qualitative; Supportive care; Survivorship; Systematic review.

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