Establishing Psychosocial Palliative Care Standards for Children and Adolescents with Cancer and Their Families: An integrative review

Abstract

Background: Despite standardization in disease assessments and curative interventions for childhood cancer, palliative assessments and psychosocial interventions remain diverse and disparate.

Aims: Identify current approaches to palliative care in the pediatric oncology setting to inform development of comprehensive psychosocial palliative care standards for pediatric and adolescent patients with cancer and their families. Analyze barriers to implementation and enabling factors.

Design: PRISMA guidelines framed the search strategy and reporting. Data analysis followed integrative review methodology.

Data Sources: Four databases were searched in May 2014 with date restrictions 2000-2014: PubMed, Cochrane, PsycINFO and SCOPUS. A total of 182 studies were included for synthesis. Types of studies included randomized and nonrandomized trials with or without comparison groups, qualitative research, prior reviews, expert opinion, and consensus report.

Results: Integration of patient, parent, and clinician perspectives on end-of-life needs as gathered from primary manuscripts (using NVivo coding for first order constructs) revealed mutual themes across stakeholders: holding to hope, communicating honestly, striving for relief from symptom burden, and caring for one another. Integration of themes from primary author palliative care outcome reports (second order constructs) revealed the following shared priorities in cancer settings: care access; cost analysis; social support to include primary caregiver support, sibling care, bereavement outreach; symptom assessment and interventions to include both physical and psychological symptoms; communication approaches to include decision making; and overall care quality.

Conclusion: The study team coordinated landmark psychosocial palliative care papers into an informed conceptual model (third order construct) for approaching pediatric palliative care and psychosocial support in oncology settings.

Keywords: literature review, palliative care, psychosocial, pediatric oncology, integrative

Funding Source: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors. This work was supported in part by the Intramural Program of the National Cancer Institute, Center for Cancer Research.

What is already known about the topic?

- Earlier integration of palliative care with psychosocial support for family members has been recommended as a critical component of comprehensive care of children and adolescents with cancer
- While many descriptive reports speak to the benefits of palliative care, currently there is a paucity of synthesized data depicting whether youth with cancer and their families should be introduced to palliative care early in the disease process and how psychosocial support should include family members

What this paper adds?

- This integrative review considers the potential for early integration of palliative care in the pediatric cancer setting to support the standardization of pragmatic, psychosocial, and communication needs of youth with cancer and their families

- By including patient, parent, and clinician perspectives as voiced in primary manuscripts, this integrative review prioritizes primary stakeholder perspectives

Implications for practice, theory or policy?

- Our findings reveal that primary family caregivers often feel over-extended during the progressing illness trajectory; siblings and grand-parents feel under-recognized and under-supported by the care team; and that the larger family unit fears being forgotten during bereavement
- Our findings reveal a mutual domain of patients, primary caregivers, family unit, and clinicians striving and yearning to best care for one another; a finding with potential to inform and advise collaborative future best practice interventions
- This review maps what is known about palliative care and psychosocial services in pediatric cancer care through integrative synthesis of published data for navigation of improved practices and standardized guideline development