

Identifying Indicators of Quality Palliative and End-of-Life Care for Children with Cancer

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BACKGROUND

It is now widely endorsed that principles of palliative care (PC) should be integrated into the routine care of many children diagnosed with cancer - not only those at the end-of-life (EOL).¹ However:

- ❖ Health care professionals (HCP) who provide care to children with cancer report receiving little training in PC.
- ❖ Families of children with cancer report several aspects of care that are not optimal.

To address these issues we will roll-out a comprehensive, evidence-based curriculum, Education in Palliative and End-of-Life Care for Pediatrics (EPEC®-Pediatrics), to HCP who care for children with cancer.

We will assess the impact of the EPEC®-Pediatrics curriculum on the quality of palliative and EOL care; however, we must first identify indicators of quality of care.

PURPOSE

The purpose of our systematic literature review was to :

- 1) Identify potential structure, process, and outcome indicators of quality palliative and end-of-life care for children with cancer and their families, and
- 2) Identify reliable and valid methods of measurement for these indicators.

METHODS

Database subject headings and text words were used to retrieve relevant articles within the following electronic databases: CINAHL, Embase, and MEDLINE

- ❖ Key search terms included disease type ("neoplasms"), studies of interest ("palliative care/therapy", "terminal/hospice care", "advance care planning/advance directives/living wills", "withholding treatment or treatment withdrawal") and indicators ("outcome assessment/health care" and "quality of life")
- ❖ Results were limited to studies in children, published in English since 2003.
- ❖ Book chapters, theses, and conference abstracts were excluded

An iterative process was used to screen articles titles and abstracts for relevance and then review the selected full articles.

- ❖ Two reviewers were involved at each level of the review process
- ❖ Inter-rater reliability was 95%

Data extracted from each article included:

- ❖ Sample type (e.g., ill child, sibling, parent, HCP)
- ❖ Age range of sample; sample size; sample exclusions
- ❖ Stage of disease (e.g., diagnosis, ongoing care, EOL)
- ❖ Key findings and quality indicators identified
- ❖ Instruments used to measure indicators
- ❖ Study (or instrument) limitations

Figure 1: Systematic Literature Review Process

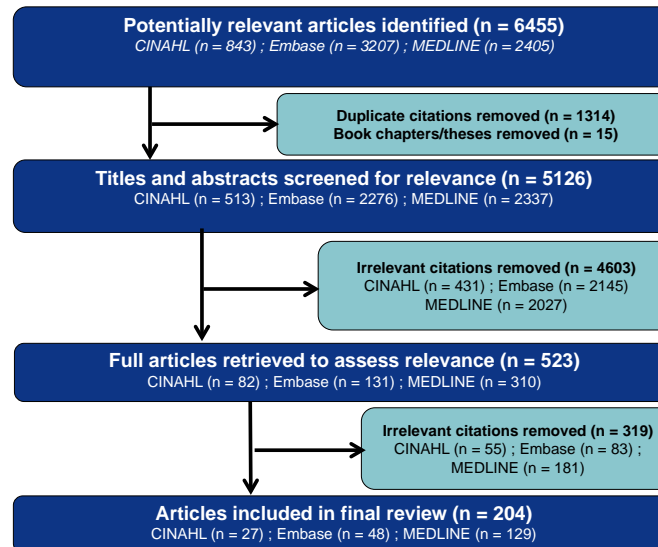
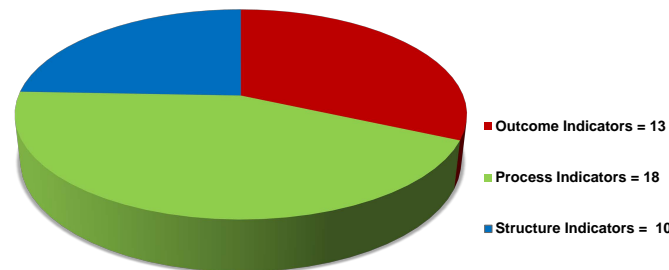


Figure 2. Number of Indicators Identified (by type)



REFERENCES

1. Waldman E, Wolfe J. Palliative care for children with cancer. *Nat Rev Clin Oncol*, 2013; 10: 100-107

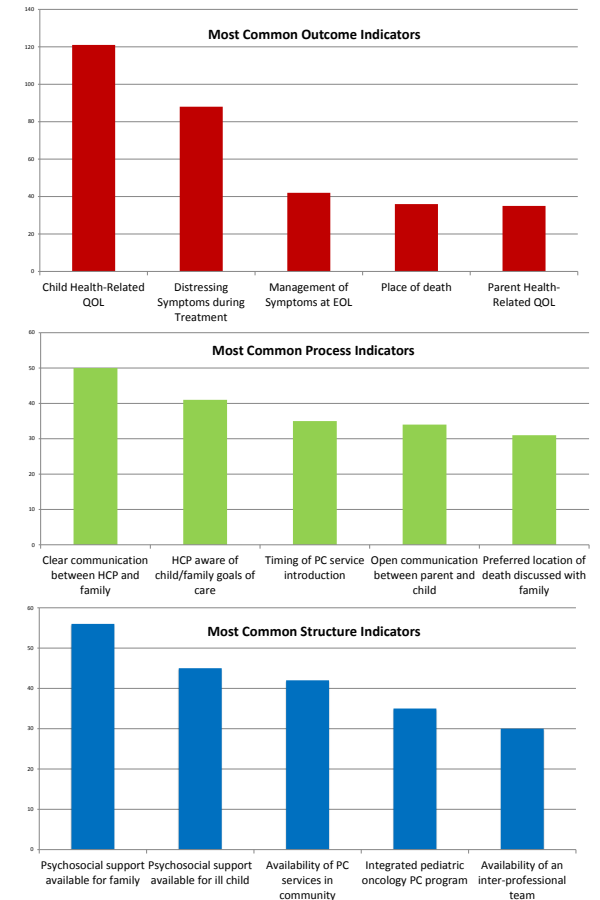
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RESULTS

6455 articles initially identified; 204 included for full review (Figure 1)

Most indicators were related to processes of care (Figure 2)



NEXT STEPS

Results will be shared with the larger research team and project partner organizations at a planning meeting in May 2014. Representatives of our partner organizations will be asked to provide input on which indicators should be chosen to measure the impact of the EPEC®-Pediatrics curriculum roll-out in our project. Quality of palliative and EOL care will be assessed according to the chosen indicators in the fall of 2014 and summer of 2016 - before and after the curriculum roll-out.