

CADTH RAPID RESPONSE REPORT: SUMMARY OF ABSTRACTS

# Pediatric Palliative Care Assessment Tools in the Home-Care Setting: Guidelines

Service Line:	Rapid Response Service
Version:	1.0
Publication Date:	August 02, 2019
Report Length:	6 Pages

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**Cite As:** *Pediatric Palliative Care Assessment Tools in the Home-Care Setting: Guidelines*. Ottawa: CADTH; 2019 August. (CADTH rapid response report: summary of abstracts).

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**Funding:** CADTH receives funding from Canada's federal, provincial, and territorial governments, with the exception of Quebec.

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## Research Question

What are the evidence-based guidelines regarding home-care assessments for pediatric palliative-care patients?

## Key Findings

One evidence-based guideline was identified regarding home-care assessments for pediatric palliative-care patients.

## Methods

A limited literature search was conducted by an information specialist on key resources including MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), the Cochrane Library, the University of York Centre for Reviews and Dissemination (CRD) databases, the websites of Canadian and major international health technology agencies, as well as a focused Internet search. The search strategy was comprised of both controlled vocabulary, such as the National Library of Medicine’s MeSH (Medical Subject Headings), and keywords. The main search concept was pediatric palliative care. A search filter was applied to limit retrieval to guidelines. The search was also limited to English language documents published between January 1, 2014 and July 29, 2019. Internet links were provided, where available.

## Selection Criteria

One reviewer screened citations and selected studies based on the inclusion criteria presented in Table 1.

**Table 1: Selection Criteria**

<b>Population</b>	Pediatric palliative-care patients (0 to 18 years) within the home or community setting
<b>Intervention</b>	Pediatric palliative care assessments or pediatric home care assessments to determine level of care (e.g., scoring tools, or assessment tools that assist with the needs and level of care required)
<b>Comparator</b>	Not applicable
<b>Outcomes</b>	Guidelines
<b>Study Designs</b>	Evidence-based guidelines

## Results

Rapid Response reports are organized so that the higher quality evidence is presented first. Normally, health technology assessment reports, systematic reviews, and meta-analyses are presented first; however, in reports where guidelines are primarily sought, the aforementioned evidence types are presented in the appendix

One evidence-based guideline was identified regarding home-care assessments for pediatric palliative-care patients.

Additional references of potential interest are provided in the appendix.

## Overall Summary of Findings

One evidence-based guideline<sup>1</sup> was identified regarding home-care assessments for pediatric palliative-care patients. This guideline, published by the National Institute for Health and Care Excellence (NICE), recommends using parallel planning for pediatric palliative-care patients. This type of planning accounts for the unpredictability of conditions in pediatric palliative-care patients, creating multiple plans of care and using the type of plan that best suits the patient and their individual circumstances. Additionally, NICE recommends assessing whether a child is ready for an Advance Care Plan (e.g., detailing the child's condition, managing symptoms, and wishes) while including a multidisciplinary team in the care plan.

## References Summarized

### Guidelines and Recommendations

1. National Institute for Health Care and Excellence. End of life care for infants, children and young people with life-limiting conditions: planning and management. (*NICE guideline NG61*) 2016 Dec; <https://www.nice.org.uk/guidance/ng61>. (Accessed 2019 Aug 2).

## Appendix — Further Information

### Systematic Reviews

#### *Alternative Intervention – Strategies for Symptom Relief*

- Knops RR, Kremer LC, Verhagen AA; Dutch Paediatric Palliative Care Guideline Group for Symptoms. Paediatric palliative care: recommendations for treatment of symptoms in the Netherlands. *BMC Palliat Care*. 2015 Nov 05;14:57.  
[PubMed: PM26542477](#)

#### *Guidelines Not Specified*

- Friedel M, Aujoulat I, Dubois AC, Degryse JM. Instruments to measure outcomes in pediatric palliative care: a systematic review. *Pediatrics*. 2019 Jan;143(1). pii: e20182379.  
[PubMed: PM30530504](#)
- Aslakson R, Dy SM, Wilson RF, et al. Assessment tools for palliative care. Technical brief no. 30 (Prepared by Johns Hopkins University under Contract No. 290-2015-00006-I.) AHRQ Publication No. 14-17-EHC007-EF. Rockville (MD): Agency for Healthcare Research and Quality; 2017 May;  
[https://effectivehealthcare.ahrq.gov/sites/default/files/pdf/palliative-care-tools\\_technical-brief-2017.pdf](https://effectivehealthcare.ahrq.gov/sites/default/files/pdf/palliative-care-tools_technical-brief-2017.pdf). (Accessed 2019 Aug 2).
- Coombes LH, Wiseman T, Lucas G, Sangha A, Murtagh FE. Health-related quality-of-life outcome measures in paediatric palliative care: a systematic review of psychometric properties and feasibility of use. *Palliat Med*. 2016 12;30(10):935-949.  
[PubMed: PM27247087](#)

### Non-Randomized Studies

- Freeman S, Hirdes J, Stolee P, et al. Care planning needs of palliative home care clients: development of the interRAI palliative care assessment clinical assessment protocols (CAPs). *BMC Palliat Care*. 2014;13(1):57-84.  
[PubMed: PM25550682](#).

### Guidelines and Recommendations

#### *Alternative Population - Not Specific to Pediatric Populations*

- BC Centre for Palliative Care. B.C. inter-professional palliative symptom management guidelines. New Westminster (BC): The Centre; 2019 Mar: <https://www.bc-cpc.ca/cpc/wp-content/uploads/2019/03/BCPCClinicalBestPracticesInteractiveMarch2019.pdf>. (Accessed 2019 Aug 2).
- National Consensus Project for Quality Palliative Care. Clinical practice guidelines for quality palliative care, 4th edition. Richmond (VA): National Coalition for Hospice and Palliative Care; 2018: <http://www.nationalcoalitionhpc.org/ncpl/>. (Accessed 2019 Aug 2).

## *Unclear Methodology*

9. Saskatchewan Ministry of Health. Home care policy manual. Regina (SK): Government of Saskatchewan; 2015 Sep: <http://publications.gov.sk.ca/documents/13/29232-Home%20Care%20Policy%20Manual%202016.pdf>. (Accessed 2019 Aug 2).

## Review Articles

10. Boyden JY, Curley MAQ, Deatrick JA, Ersek M. Factors associated with the use of U.S. community-based palliative care for children with life-limiting or life-threatening illnesses and their families: an integrative review. *J Pain Symptom Manage*. 2018 01;55(1):117-131.  
[PubMed: PM28807702](#)