

 PALLIATIVE CARE

Gaps between ideal and reality

Increasingly, it is recognized that palliative care is a crucial part of the treatment trajectory for patients with advanced-stage cancer. As part of this recognition, the National Consensus Project and National Quality Forum released a set of clinical practice guidelines and preferred practices. These guidelines were drawn up with adults in mind, and now the assessment of palliative care in paediatric patients has been considered by a team led by Alisha Kassam and Joanne Wolfe.

In this study, questionnaires were distributed to 75 bereaved parents, and 48 oncology clinicians. Kassam explains that the aim of the questionnaires were: “evaluating which elements of palliative care delivery recommended by the National Consensus Project guidelines bereaved parents and clinicians would have liked children to receive, and their accessibility to these valued elements.”

The responses to the questionnaire showed that 15 of the 20 core elements of palliative care were considered to be

important by both parents and clinicians. However, only three of the elements were accessible for more than 60% of the time.

As Kassam points out: “this is the first study that has evaluated parental and clinician preferences for how palliative care should be delivered to children and represents a critical step towards defining and measuring quality palliative care standards that incorporate patient and family needs.” The gap between what is considered important and what is accessible demonstrates a clear area to move concerted effort going forward. Wolfe agrees: “this disparity suggests a critical need to improve access to high quality paediatric palliative care for children with cancer.”

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