

Cancer. 2024 Aug 18. doi: 10.1002/cncr.35518. Online ahead of print.

Bereaved parent preferences on quality end-of-life care for children with cancer in the South

Isaac Martinez ¹, Erin Currie ², Elizabeth S Davis ³, Rohail Kumar ⁴, Valerie Lawhon ⁵, Jennifer M Snaman ^{6 7 8}, Raba B Tefera ¹, Smitta Bhatia ^{1 9}, Abby R Rosenberg ^{6 7 8}, Emily E Johnston ^{1 9}

Affiliations

PMID: 39155428 DOI: [10.1002/cncr.35518](https://doi.org/10.1002/cncr.35518)

Abstract

Purpose: The authors sought to understand bereaved family preferences for end-of-life (EOL) care, particularly among Black families and those in the South.

Methods: Semi-structured interviews were conducted with parents of children who died of cancer ≥ 6 months before at Children's of Alabama. Themes were identified via content analysis. Quotes related to medical intensity, chemotherapy, and location of death (LOD) were scored on 5-point Likert scales, ranging from 1 (comfort care, chemotherapy, or home death) to 5 (medically intense care, avoidance of chemotherapy, or hospital death).

Results: Twenty-seven bereaved parents (12 Black) were interviewed. Children died at a mean of 13.1 years (SD = 6.1 years) and a median of 3 years before the interview (range = 1-12 years). Ten children (42%) had central nervous system tumors and the majority (63%) died in the hospital. Family decision-making involved maintaining hope, not causing harm, doing what was best for their child and themselves, and religious beliefs. There was no clear preference for home versus hospital death (3.0 [1.8-4.0]). Instead, parents considered their child's desires and/or medical needs, siblings, and prior experiences with death. To have a comfortable death, parents highlighted the need for comprehensive education about their child's EOL, a caring and comfortable environment, and 24/7 access to their care team. Families expressed a dual preference for comfort care (1.8 [1.3-2.8]) and chemotherapy (3.5 [2.7-4.1]) at EOL.

Conclusions: Families did not see chemotherapy and comfort care as conflicting goals. They sought quality care emphasizing flexibility, quality time with their child, and open access to their care team, regardless of LOD.

Keywords: end-of-life; oncology; palliative care; pediatrics.

© 2024 American Cancer Society.

[PubMed Disclaimer](#)