

Methods. Among 2,579 KT candidates and 1,234 KT recipients (12/2008-2/2020), we assessed the presence of ACP and PC through chart review. ACP and PC correlates were identified via multivariable logistic regression.

Results. KT candidates' and recipients' mean ages were 55 and 53 years, respectively; 46.6% and 40.5% were Black. 21.4% of candidates had ACP; prevalence was higher in older (18-64 years = 19.9%, 65+ = 25.7%) and White candidates (White = 24.4%, Black = 19.1%, Hispanic = 15.0%, other race = 21.0%). 34.9% of recipients had ACP; similarly, older (18-64 years = 31.7%, 65+ = 47.1%) and White (White = 39.5%, Black = 31.2%, Hispanic = 26.3%, other = 26.6%) patients had higher prevalence. After adjustment, older age (OR = 1.85, 95% CI 1.35-2.53) and Black race (OR = 0.68, 95% CI 0.51-0.91) were associated with ACP only among KT recipients. PC prevalence was 4.3% in candidates and 5.1% in recipients and higher in older candidates (18-64 years = 3.8%, 65+ = 5.6%, $p = 0.046$) and recipients (18-64 years = 3.8%, 65+ = 10.0%, $p < 0.001$). After adjustment, only Black race (OR = 0.65, 95% CI 0.42-0.99) was associated with PC in candidates, while only older age (OR = 2.47, 95% CI 1.38-4.41) was associated with PC in recipients.

Conclusion. KT candidates and recipients experience a lower prevalence of ACP and PC compared to patients with chronic illness in the United States. Importantly, significant racial and ethnic disparities exist in ACP.

Impact. PC remains underutilized among KT candidates and recipients, more so for Black and Hispanic patients, and may improve symptom burden and ACP.

Parent Priorities in End-of-Life Care for Children with Cancer (CO202C)

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Outcomes.

1. Understand the landscape of end-of-life care quality measurement for children with serious illness
2. Discuss a unique research study that sought to establish parent priorities for end-of-life care quality measurement for children with cancer

3. Place study findings in a context of existing literature and future steps

Importance. Robust quality measures (QMs) to benchmark end-of-life care for children with cancer do not currently exist. We previously developed 26 patient-centered QMs through diverse stakeholder engagement.

Objectives. We sought to prioritize the previously identified QMs among parents who lost a child to cancer.

Methods. We recruited bereaved parents from the U.S. to participate in an online survey, employing a discrete choice experiment with maximum difference scaling. In each survey question, 4 QMs were presented, and parents were asked to select the most and least important measures. Each of the 26 QMs was presented an equal number of times, in different permutations. We used hierarchical Bayesian multinomial logistic regression to derive average importance scores for each QM, equivalent to the overall probability of a QM being selected as most important. Importance scores were scaled proportionally from 0 to 100, such that a QM with a score of 5 is considered 5× more important than a QM with a score of 1. This approach enabled interpretation of the relative importance of QMs.

Results. Sixty-one bereaved parents participated. Highest-priority QMs included having a child's symptoms relieved (average importance score 9.3 [95% credible interval (CI) 9.1, 9.4]), feeling that a child's needs are heard by the healthcare team (8.4 [8.1, 8.7]), and having an end-of-life care experience that matches a family's goals and preferences (7.4 [6.8, 8.1]). Lowest-priority QMs included avoiding chemotherapy (0.3 [0.2, 0.5]), offering psychosocial support for parents (1.0 [0.6, 1.5]), and avoiding the intensive care unit (1.1 [0.7, 1.4]).

Conclusions. Bereaved parents prioritized end-of-life QMs focused on symptom management and goal-concordant care, de-prioritizing their own psychosocial well-being. Parents further characterized QMs that quantify or restrict healthcare use as substantially less important.

Impact. This study informs future patient-centered strategies to measure care attributes that matter most to families of children with advanced cancer.

A Lay Navigator Intervention for Caregivers of Hispanic Persons with Alzheimer's and Related Dementias (AD/RD): Feasibility and Acceptability (CO202D)

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