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Study Finds Pediatric Oncology Programs Lack Sufficient Psychosocial Providers

WILMINGTON, Del. (April 7, 2025) — Families facing a childhood cancer diagnosis experience a range of psychological, social, and emotional stressors, from anxiety to financial strain to sibling concerns. A study led by Nemours Children's Health researchers shows that while most pediatric oncology programs offer some psychosocial resources to help families handle these stressors, few have the recommended breadth and depth of psychosocial providers to deliver comprehensive care.

"As tremendous progress has been made in treating pediatric cancers, over time we have seen the need for comprehensive, evidence-based psychosocial interventions to help families with the stress and strain of these life-threatening diagnoses, as well as the side effects and late effects of cancer treatment," said the study's senior author, Anne E. Kazak, PhD, Enterprise Director of the Nemours Center for Healthcare Delivery Science. "Our study shows that there is still not, in most cases, an adequate level of staffing to provide psychosocial resources for families dealing with a childhood cancer diagnosis," Kazak said.

In 2015, an interdisciplinary group of experts and cancer advocates, including Nemours Children's researchers, published the first evidence-based Standards for the Psychosocial Care of Children with Cancer and their Families, to establish best practices in this area of oncology care.

A new study published in *Pediatric Blood & Cancer* reviews national benchmarks to help pediatric cancer programs assess their resources for meeting the Standards, and also gives families information about available assistance. Kazak and fellow researchers, in collaboration with cancer advocates, also compared current psychosocial staffing resources in pediatric oncology programs with a prior study they conducted in 2016. They surveyed clinical leaders at 129 pediatric oncology programs around the United States, all of which are members of the Children's Oncology Group.

Overall, the researchers found that while most programs offer some psychosocial resources, very few have sufficient staff to meet the guidelines set forth by the Standards. Key findings:

- In 2023, programs in the study had approximately 1 full-time (FTE) social worker per 40 patients; 1 FTE child life specialist per 50 patients; 1 FTE psychologist per 100 patients; 1 FTE neuropsychologist per 100 patients; and 1 FTE psychiatrist per 200 patients.
- In 2023, while social workers were available in 97.2% of programs and child life specialists were available in 92.5%, other psychosocial experts were less well represented. Psychologists were present in 69.2% of programs; neuropsychologists in 39.3%; and psychiatrists in just 15.0%.
- On average, respondents felt that availability of psychosocial staff levels was a barrier to the provision of care (2.81 on a 4-point scale). They cited lack of funding for psychosocial positions as a barrier (3.31 on a 4-point scale). Both ratings are unchanged from 2016.
- Availability of Spanish-speaking psychosocial professionals increased. The percentage of programs with Spanish-speaking social workers rose from 28.9% in 2016 to 38.5% in 2023.
- Half of the survey respondents said the COVID-19 pandemic had decreased the availability of psychosocial staff, and more than a third said staff turnover had increased.

Lori Wiener, PhD, Director of the Psychosocial Support and Research Program at the Center for Cancer Research, National Cancer Institute, National Institutes of Health, was instrumental in designing the Standards in 2015. She explained that a well-resourced psychosocial team can be instrumental in improving patient experiences and long-term outcomes.

"With appropriate psychosocial resources, children and their family members can be prepared for how to manage the emotional, psychological, social, and spiritual impact of childhood cancer, which can lead to positive coping and personal and family growth," she said. "Psychosocial services can result in reduced feelings of anxiety, depression, and fear due to uncertainties surrounding the diagnosis treatment and life after cancer."

The authors said the study results indicate that comprehensive, multidisciplinary psychosocial staff is needed across centers. Future research will examine which of the Standards have the greatest unmet need, and how those needs can be addressed.

The parent perspective

Kazak and Wiener have established a research partnership with two patient advocacy groups. Victoria Sardi-Brown, PhD, LPC, founder of the Mattie Miracle Cancer Foundation, and Kimberly Buff, founder and executive director of Momcology, have collaborated on several studies with the team, and in this case, lent the unique perspective of parents who have navigated a child's cancer diagnosis.

"Children and their families endure countless stressors each day, and having access to psychosocial care can transform a horrible day into a more manageable one," said Sardi-Brown. "When the emotional and social needs of families are considered, children are more likely to adhere to the treatment plan, families are more likely to feel empowered to support their children and interact with the healthcare team, and most of all, the quality of life for children and families improves."

She explained that she experienced the benefits of psychosocial care when her son, Mattie, was receiving treatment for osteosarcoma.

“When his psychosocial needs were met, he was happier, he was engaged with his treatment team, and he was less frightened and more secure to participate in scans, procedures, and hospitalizations. Having access to psychosocial care may not change the trajectory of the disease, but it impacts the day-to-day health and well-being of children and their families. Such emotional and social stability is vital to the overall effectiveness of the medicine.”

Buff echoed the importance of support for the child and family throughout all stages of a child’s cancer treatment.

“Families are often faced with making rapid, high-stakes decisions that can implicate the child's future throughout the duration of treatment. This reality underscores the urgent need for prioritized psychosocial support. By providing this essential care, we empower patients, their families, and healthcare providers to tackle these challenges together with resilience and clarity,” Buff said.

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About Nemours Children's Health
Nemours Children’s Health is one of the nation’s largest multistate pediatric health systems, which includes two freestanding children's hospitals and a network of more than 70 primary and specialty care practices. Nemours Children's seeks to transform the health of children by adopting a holistic health model that utilizes innovative, safe, and high-quality care, while also addressing children’s needs well beyond medicine. In producing the highly acclaimed, award-winning pediatric medicine podcast Well Beyond Medicine, Nemours underscores that commitment by featuring the people, programs and partnerships addressing whole child health. Nemours Children's also powers the world’s most-visited website for information on the health of children and teens, Nemours KidsHealth.org.

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