



# Research Week 2020

## Mental Health of Families during Childhood Cancer Treatment and Survivorship

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### Keywords

pediatric oncology; mental health; health experiences

### Abstract

#### Background

There are few studies on the long-term psychological impact of caring for a child who underwent treatment and survived cancer. While young survivors of childhood cancer report a need for psychological support during and after treatment, little is known about this experience from the caretaker's perspective.

#### Methods

Parents of childhood cancer survivors participated in semi-structured, qualitative interviews conducted by researchers trained in the 'Database of Individual Patient Experiences' (DIPEX) methodology. Interviews focused on identifying topics most important to patients and families throughout the process of cancer diagnosis, treatment, and survivorship. 29 interviews were completed thus far. Using NVivo, interview transcripts were dual-coded and analyzed using the constant comparison method to identify both common and divergent themes. Identified themes were deliberated until consensus was reached.

#### Results

In preliminary analysis of the initial 22 interviews, the following themes emerged: (1) need for mental health support for families during and after cancer treatment; (2) difficulty asking for and accessing psychological help while in caretaker role; and (3) recognition and diagnosis of posttraumatic stress disorder after treatment. Prevalent barriers identified by participants to mental health access included feeling overwhelmed by cancer diagnosis and treatment, fear of acknowledging cancer diagnosis, and an intense focus centered around caring for their children and not themselves. Multiple participants suggested providing mental health counselors to caretakers during and after treatment as part of standard practice.

#### Conclusions

Despite the success of completing treatment and surviving cancer, many caretakers of childhood cancer survivors reported symptoms of depression and anxiety surrounding the profound impact of cancer on their lives. Solutions should focus on implementing emotional support interventions for families during and after cancer treatment as standard care. There is a need to improve psychological interventions for family members during and after the traumatic experience of caring for a child with cancer.

