
Abstract

Identifying Parental Needs When Caring for a Child or Adolescent With Cancer: Participatory Design Study

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Abstract

Background: Survival possibilities among children and adolescents (referred to as “children”) with cancer have increased, resulting in more children and parents living with sequelae and psychological distress, respectively. Childhood cancer treatment is intensive and long term and affects the everyday life and functioning of the whole family, including daily and social life restrictions and hospitalizations, which force the parents to split up between the hospital and home to care for both the ill child and siblings and manage their jobs and homelife routines. Adequate parental coping strategies are essential for family adjustment and the child’s coping ability. Parenting a child with cancer, however, is challenging and stressful.

Objective: This study aimed to identify parental needs when caring for a child with cancer.

Methods: Using a participatory design approach, we generated data through field studies and semistructured interviews with parents of children receiving treatment at Odense or Aarhus University Hospital and focus group interviews with parents of children who have completed treatment within the past 2 years.

Results: The parents felt trapped in an endless, emotional roller-coaster ride of fear, hope, grief, and mental and emotional exhaustion and had very limited resources for self-care. The presence of support from peers, health care providers, and relatives was a facilitator of successfully coping with the illness. In contrast, full-time isolation in the hospital, due to COVID-19 restrictions, was a barrier and linked with feelings of loneliness. Loneliness was also experienced as navigating difficult emotions when responding differently from the spouse or not feeling understood by relatives.

Conclusions: Parents of children with cancer face many stressors that may become a psychological burden. New innovative approaches to provide psychosocial support, taking into account that the families are periodically isolated, are needed. For this goal, technological solutions may be useful and should be the focal point of this study’s experimental design phase.

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KEYWORDS

pediatric cancer; parental caregiving; participatory design

Conflicts of Interest

None declared.

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