

Original Article

Economic Impact of Advanced Pediatric Cancer on Families

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Abstract

Context. Despite emerging evidence of substantial financial distress in families of children with complex illness, little is known about economic hardship in families of children with advanced cancer.

Objectives. To describe perceived financial hardship, work disruptions, income losses, and associated economic impact in families of children with advanced cancer stratified by federal poverty level (FPL).

Methods. Cross-sectional survey of 86 parents of children with progressive, recurrent, or nonresponsive cancer at three children's hospitals. Seventy-one families with complete income data (82%) are included in this analysis.

Results. Parental work disruptions were prevalent across all income levels, with 67 (94%) families reporting some disruption. At least one parent quit a job because of the child's illness in 29 (42%) families. Nineteen (27%) families described their child's illness as a great economic hardship. Income losses because of work disruptions were substantial for all families; families at or below 200% FPL, however, were disproportionately affected. Six (50%) of the poorest families lost more than 40% of their annual income as compared with two (5%) of the wealthiest families ($P = 0.006$). As a result of income losses, nine (15%) previously nonpoor families fell from above to below 200% FPL.

Conclusion. The economic impact of pediatric advanced cancer on families is significant at all income levels, although poorer families suffer disproportionate losses. Development of ameliorative intervention strategies is warranted. *J Pain Symptom Manage* 2014;47:594–603. © 2014 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

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Key Words*Pediatric, oncology, palliative care, financial, poverty, disparities***Introduction**

Approximately 12,000 U.S. children will be diagnosed with cancer this year and 17% will die of their disease.^{1–3} At any one time, thousands of children are living with advanced cancer. Recent data are elucidating the economic impact of pediatric complex chronic illness on families in broad strokes, yet none have focused on the experience of financial burden in families of children with advanced cancer.^{4–6}

Pediatric palliative care seeks to enhance quality of life and minimize suffering through the provision of “competent, compassionate, and consistent care to children with chronic, complex, and/or life-threatening conditions and their families.”⁷ As efforts to expand access to pediatric palliative care have grown, increasing attention is being paid to the diverse cohort of children with special health care needs (CSHCN)—within which children with cancer represent an important subset—who account for a significant proportion of those cared for by pediatric palliative care services.⁸ These children, who by definition suffer from “chronic physical, developmental, behavioral or emotional” conditions that necessitate health and related services of a type or amount beyond that required by children in general, present the unique challenge of chronic illness management in addition to pain and symptom management.^{7–9} As pediatric palliative care providers aim to ameliorate suffering in this population, emerging evidence suggests a need for increased attention to a nonphysical source of distress in these families—economic hardship.

National efforts to better understand patterns of utilization, and identify families at highest risk for financial burden, have been bolstered by policy initiatives—including Healthy People 2010—focused on optimizing care for CSHCN.¹⁰ Studies have reported that up to 40% of CSHCN families experience financial burden secondary to their child's illness and 25% experience work disruptions, including 13% who need to quit a job.^{11,12} Child characteristics, including younger age, condition instability, and increased functional

limitations, have been identified as risk factors for financial hardship.^{11,12} Families of CSHCN with lower socioeconomic status or without health insurance are at higher risk of financial hardship, highlighting disparities in the distribution of burden.^{11–14}

Pediatric cancer patients have been identified as children who use a disproportionate amount of health resources.^{8,9,15} In 2009, hospitalizations for children with cancer were eight days longer and cost five times more than hospitalizations for other pediatric conditions.¹⁶ Cross-sectional and retrospective studies of pediatric cancer families recapitulate risk factors and financial outcomes for less complicated CSHCN families. New diagnosis, receipt of care far from home, and prolonged hospitalizations have been identified as risk factors for financial burden, and poorer pediatric oncology families suffer disproportionate burden.^{5,6,17–19} Financial impact far in excess of the general CSHCN population has been described, including 68% to 74% of pediatric oncology families with financial burden secondary to illness,^{5,19} and a full 64% to 85% with work disruptions, including 35% to 45% needing to quit a job.^{4–6}

Limitations of this emerging literature include inadequate data on economic consequences to families of children with advanced cancer, which we hypothesize would be even greater given the prolonged and intensive illness experience. In this study, we aimed to describe patterns of financial impact experienced by families of children living with advanced cancer, as reported by parents during their child's illness. We describe economic outcomes—perceived financial hardship, work disruptions, and income losses secondary to a child's illness—stratified by family poverty level at three pediatric hospitals.

Methods

Data for this analysis come from the cross-sectional baseline Survey about Caring for Children with Cancer (SCCC), part of the Pediatric Quality of Life and Evaluation of

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