

Measuring the Financial Stress of Childhood Cancer & Survivorship



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INTRODUCTION

The diagnosis of cancer in a child typically galvanizes families and communities to make extraordinary commitments and sacrifices that prioritizes a child's well-being above many other family, financial and employment considerations.

Increases in childhood cancer survival rates are the result of a national network of children's hospitals and academic medical centers providing treatment.

However, access to successful treatment also depends on financial, community and psychosocial support structures.

BACKGROUND

Families battling childhood cancer can face extraordinary financial challenges in access to care.

Insurance barriers, coverage limitations and denials, high copays and extraordinary out-of-pocket costs threaten families' ability to ensure supports necessary for successful treatment.

Families also face employment, childcare and transportation challenges to obtaining quality care.

OBJECTIVE

To conduct a pilot study around childhood cancer access challenges for the purpose of determining potential public policy responses to eliminate impediments to the delivery of quality care .

METHODS

From April 18, 2017 to May 31, 2017, we surveyed pediatric cancer patients, caregivers and survivors through an online survey tool

Questions identified demographic and geographic attributes, type of insurance coverage, incidence and reason for insurance denials, degree and source of financial stress, out-of-pocket costs, survivorship follow-up as well as measurements on employment and transportation.

The survey also included questions on experiences with drug shortages during treatment.

RESULTS

Figure1: Type of Survey Respondents (N=343)

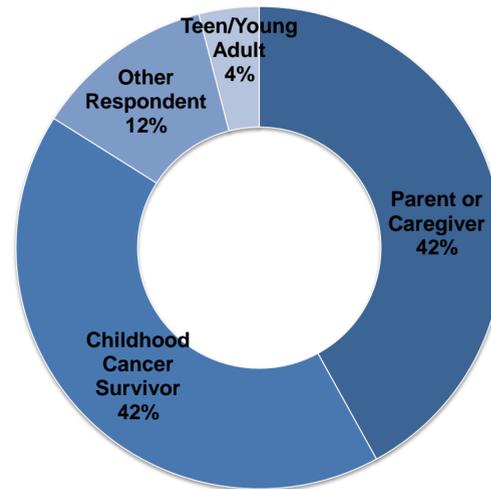
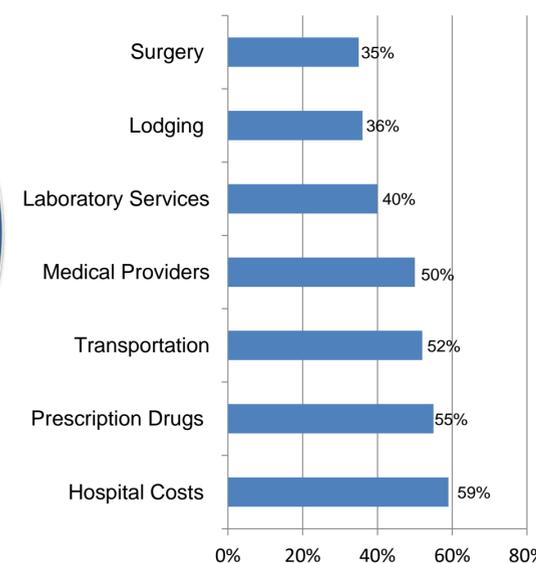


Table 1: Sources of Financial Distress Parents/Caregivers (n=63)



39% reported annual out-of-pocket costs exceeding \$5,000

RESULTS

Beyond medical expenses, employment and transportation costs were of greatest concern, with 87% reporting compromised work schedules and over half reporting trouble getting their child to and from appointments.

For adult survivors 27% reported not receiving follow-up care at a late effects clinic .

In addition, 24% reported that their cancer care impacted their ability to pursue higher education and 30% reported that the cost of their medical care impacted their career course or job choice.

CONCLUSIONS

This joint CCA/PAF survey identified significant financial challenges, both medical and non-medical, for patients, caregivers and survivors of childhood cancer.

While the science of cancer biology and precision medicine advances at a rapid pace, economic and social barriers continue to compromise the full potential of available treatments for children and survivors.

Treatment advances require identification of support systems and public policies that will increase the likelihood of children's access to treatment advances.

DISCLOSURES

The authors have no disclosures or conflicts of interest to report. An incentive for completing the survey was offered by entry into a weekly drawing for a \$100 Amazon gift card.