



The Economic Impact of Childhood Cancer

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The costs associated with childhood cancer make it a struggle for families to get by and meet their needs while also being able to get their child to lifesaving treatment. For families already living in poverty, these difficulties are often multiplied. Even when in remission, lack of funds increases the [likelihood of relapse](#) and can shift the financial course for a [family's](#) or child's future.

The National Children's Cancer Society (NCCS) conducted a survey of 449 families served and found a majority (95%) say their child's cancer caused a financial burden on their family. In this paper, the NCCS identifies and explains the financial impact a childhood cancer diagnosis can have on a family and explores possible solutions.

THE FACTS:

1 in 5

CHILDREN who receive a new diagnosis of childhood cancer are **already living in poverty**

10-15%

of US families studied were **not poor at the time of diagnosis** and became poor **during treatment for their child's cancer**

1 in 4 FAMILIES

 report **losing more than 40% of their annual household income** as a result of treatment-related work disruption—**this figure doesn't account for out-of-pocket expenses** like traveling to the hospital and extra childcare at home

1 in 3 FAMILIES

 face other work disruptions like having to quit or change jobs

Financial hardship persists for families at least **a year after treatment ends**



SHAPING THE FINANCIAL COURSE FOR THE FAMILY

The average cost associated with childhood cancer is a [startling \\$833,000](#). Ninety percent of NCCS families surveyed said they experienced an increase in expenses as a direct result of a child's diagnosis. As the authors of [a 2014 study noted](#), "The level of burden experienced by all families of children with advanced cancer—regardless of baseline family finances—is extraordinary. Families already struggling with their child's progressive or relapsed cancer are bearing an economic burden above and beyond what most Americans would deem manageable."

Sadly, nearly 40 new families will hear the dreaded words, "your child has cancer," every single day. The associated expenses, travel to treatment and loss of income are a tremendous worry. In the study mentioned above, researchers discovered [more than a quarter \(28%\) of parents](#) across all income levels said they experienced great economic hardship when going through the treatment process. That number nearly doubles for lower income levels. **Fifty percent of poor families (making \$44,000 or less for a family of four) reported extreme economic hardship, while 21% of wealthy families still said the loss of finances were substantial.**

While being a caregiver to a sick child is a full-time job, there are no benefits or pay for those who take on this role to help their child survive. Ninety-four percent of parents state they either cut hours, quit a job or quit doing overtime because of their child's illness. [Thirty-six percent](#) of families lost more than 40% of their annual income. Down the road, parents often face the implications they're less employable because of gaps in employment and the necessary leaves of absence requested.

"Almost every time we went to Philadelphia, that's time my wife has to take off work. Not only are you taking out the \$1,000 for the hotel stay, people don't realize you're also missing a week's worth of work. So not only are you out the \$1,000 but you're also out the 6-700 dollars you'd make a week for work,"
– Father of LJ, diagnosed with leukemia.

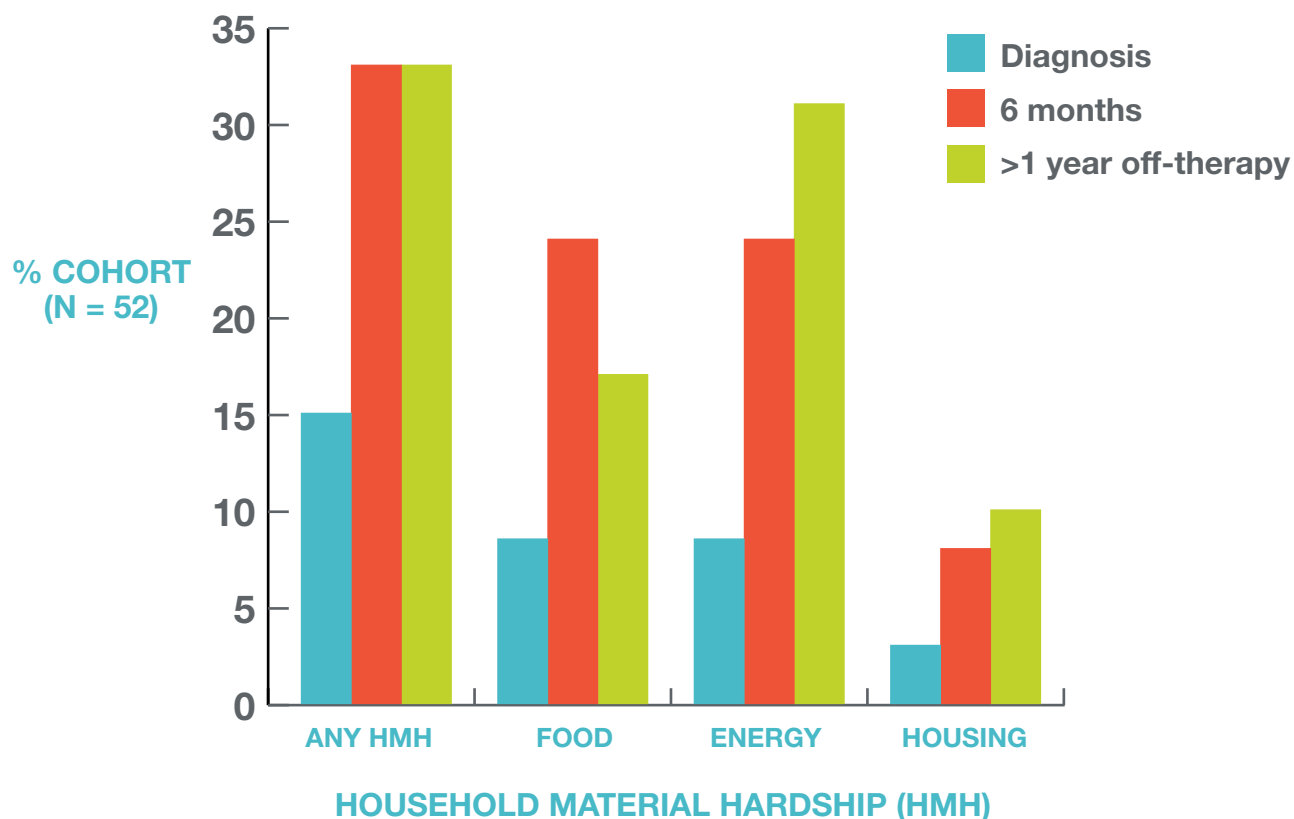
HOUSEHOLD MATERIAL HARDSHIP

The lack of very basic needs for a family have been assessed [within surveys](#) asking about the level of household material hardship (HMH). Household material hardship is a concrete measure of poverty and includes an overview of the scarcity of food and energy (utilities), and housing insecurity.

Meeting the needs of a child requiring special care can be very difficult in the best of times, but especially so when basic living needs are compromised. **Unfortunately, 30% of pediatric cancer families across income levels report HMH during the first six months of chemotherapy.** The HMH continues to increase in early survivorship (after therapy has ceased for over a year). The results are grave as HMH is associated with [lower pediatric health outcomes](#) including delayed development, cardiovascular issues, injuries and chronic illnesses. HMH can hinder adults' and children's mental health, physical health and quality of life.

It is easy, but distressing, to imagine that families already living at the poverty level are suffering from HMH. Yet even in the socioeconomically advantaged group of parents surveyed—15% experienced HMH during their child's treatment.

Persistence of HMH Post-Chemotherapy in Pediatric Oncology Families



HMH REPORTED BY:

- 15% families at diagnosis
- 33% families at 6 months
- 33% families >1 year off-therapy

(Unpublished data, manuscript in preparation)

<https://www.youtube.com/watch?v=3LeKCcPSzTY>

“You would be surprised what cancer brings into a family financially. You don’t just have your doctors and your chemo, you have all your other medicine on top of it. We have insurance...and still, it’s outrageous. There was a time in last November that if I didn’t have NCCS money, I wouldn’t have had food while I was at the hospital for 28 days,”
– Mother of Keegan, diagnosed with leukemia.

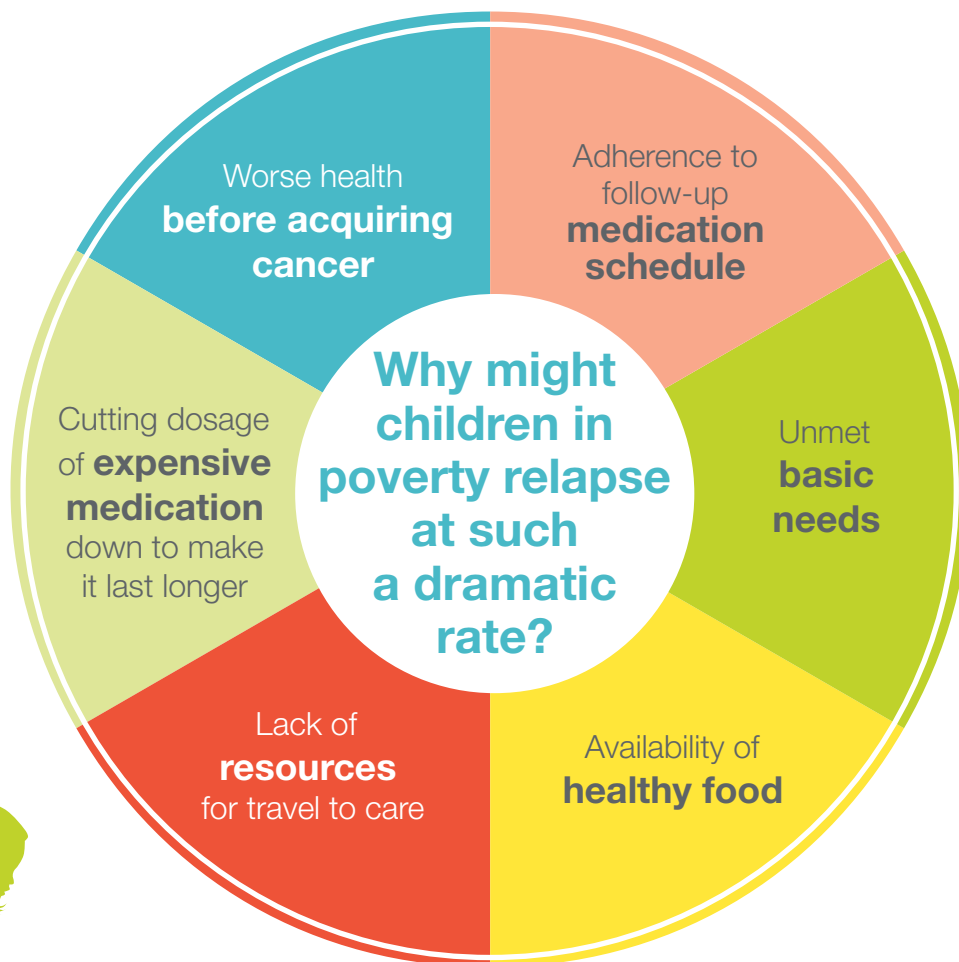
RELAPSE

The days, months and years after a child is in remission still contain worry about possible return of their cancer. Even for families who have the means and ability to get to their follow-up appointments and adhere to medication routines at home, kids relapse. While the rate of a malignancy returning varies by type of cancer, generally [long-term relapse rates](#) are around 15-25%. For children coming from a poor socioeconomic status (SES) the relapse rate is even higher.

Dr. Kira Bona of Dana-Farber/Boston Children's Cancer and Blood Disorders Center found in her research of early relapse, the overall survival rate for children living in poverty five years after diagnosis is 85%. Of the kids who experience relapse within 36 months after remission, [92% are poor children](#), compared with 48% for wealthier children.

The earlier a relapse occurs, the harder it is on the body and all the more difficult for a child to overcome. It is tougher to treat certain cancers, like acute lymphoblastic leukemia (ALL) with additional chemotherapy when relapse occurs so soon.

Outcomes can be catastrophic when families are unable to adhere to the follow-up care their child needs. [One study](#) found that when a child misses one dose of daily chemotherapy within a two-week period, the risk of relapse increases fourfold.



POSSIBLE SOLUTIONS

The National Children's Cancer Society (NCCS) covers costs surrounding treatment—primarily travel expenses such as gas, airfare and lodging. Help with these necessary logistical expenses are part of what can better position a child and family for a healthy future. Often a social worker from the hospital's pediatric oncology team is the point of contact connecting a family with the NCCS' financial assistance.

To effectively treat children facing the challenges of cancer, poverty has to be an issue integrated in models for care and hospitals appropriately staffed with a team to help.

[Findings from Dr. Kira Bona](#) and her research team have been discussed throughout this paper. Bona knows medical professionals are lauded for what they accomplish for children with modern medicine. However, she and her team are working on plans to further improve outcomes, regardless of SES level, because the fact is for every 80 children who live...20 will not.

First and foremost, medical professionals are understandably concerned with treatment and survival. To help with the tough subject of finances as well, Bona suggests [approaching all issues openly](#), and staffing pediatric oncology teams with lawyers to approach insurance issues and social workers to connect families with resources like the NCCS.

Since it is likely for 20% of children who come to the hospital to already be living in poverty, physicians should plan for a possibility of them being food insecure or experiencing material hardship. There are three areas Dr. Bona plans on incorporating into her studies surrounding financial toxicity in the realm of [Intervention Development](#).

“Our lives changed drastically. Aside from the severe emotional pain we experienced, our finances were drastically impacted, and money became extremely tight. I had to cut my work schedule in half and that made our bills seem even harder to pay. Fortunately, I was blessed with support from The National Children's Cancer Society,”

– Mother of Rosalyn, diagnosed with leukemia.

1. **SYSTEMATIC SCREENING.** Most who take their children to the doctor are accustomed to filling out a questionnaire of some sort. Often times pediatric offices hand out a one-page, simple form asking questions about safety in the home. But are these screening tools asking the important questions about a household's financial state? If not, it is impossible to address money issues from the start since they are unknown.
2. **LINKAGE.** Assuming step one was effectively carried out, next would be to connect a family with helpful resources, like the NCCS. On the supporting organization's end, applications that are easy to submit and short do a great deal to facilitate assistance to families who already have a scarcity of time and resources.
3. **NOVEL PARTNERSHIPS.** Dr. Bona's grand scheme is to find ways that big corporations, like Amazon or Uber, could be of assistance to families facing childhood cancer. For instance, she speculated that families living below the poverty line who do not have access to their own convenient transportation could be at risk in times of dire emergency. A company like Uber could be on-call for this type of urgently needed transportation to care.

CONCLUSION

So much has been accomplished in the medical world to deal with the tragedy of childhood cancer and the health concerns that come after. Innovation moves forward still with advanced research and new clinical trials. However, as more children survive cancer a large need is apparent for improved financial outcomes to ensure children and families going through childhood cancer have a safe, healthy and secure future.

The concerns and solutions here are broad based. There is not an easy answer or a quick fix, but there is hope in research, plans being formulated, and financial assistance available through the programs at the NCCS. Thankfully, 98% of families who received financial assistance from the NCCS said the help eased their troubles. Together, we will deal with the financial burdens of childhood cancer, NO MATTER WHAT.

The National Children's Cancer Society (NCCS), headquartered in St. Louis, Missouri, is a not-for-profit organization providing support to families making their way through the daunting world of childhood cancer and survivorship. With over 30 years of experience serving more than 43,000 children, the NCCS is able to take a "no matter what" approach to help families stay strong, stay positive and stay together. The NCCS has been recognized as a Better Business Bureau Accredited Charity and earned a GuideStar Platinum Seal of Transparency. For more information call 314-241-1600, visit [theNCCS.org](https://thenccs.org), or on Facebook and Twitter. To read all articles and white papers published by the NCCS, visit <https://thenccs.org/articles#>.