



Cancer-Related Financial Toxicity and its Pervasive Effects on Patients and Families:

Solving a National Health and Economic Crisis Hiding in Plain Sight



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Background

The full costs and enduring impact of cancer on patients, families and the community at large are far-reaching and immense in scale. Based on the growth and aging of the United States (US) population, direct medical expenditures for cancer are projected to total at least \$158 billion (in 2010 USD) by 2020.¹ Cancer patients and their families pay about \$4 billion a year for out-of-pocket costs² associated with

treatment, and the substantial financial effects on families can be toxic. Cancer-related financial toxicity (CRFT) is a debilitating side effect of cancer treatment.^{3,4} It occurs when the out-of-pocket costs associated with cancer treatment (e.g. travel, hotels, co-payments, deductibles, etc.) are high relative to a family's diminished income, as treatment often requires patients and families to reduce work hours significantly.^{3,5,6} Moreover, CRFT has wide-ranging social and clinical consequences including reduced quality of life, increased psychosocial hardship, poorer treatment adherence and decreased survival.^{3-5,7-9} While insurance coverage is crucial to help patients and families absorb the direct medical expenses of cancer, it does not necessarily protect against CRFT, as most patients are underinsured and health insurance does not pay for the non-medical and indirect costs of cancer care.^{10,11}

A report on the global economic costs of cancer found that the indirect costs associated with cancer treatment in the US represent about 1.73% of its GDP.¹² In 2016, Family Reach provided more than 1,400 financial assistance grants, totaling more than \$1,740,000, to patients and families for the indirect cost of treating cancer. These families received care at over 185 hospitals across the country. Seventy-two percent of the families reported losing more than 50% of their income since the time of original diagnosis. The majority of Family Reach grants (67%) kept

Cancer patients and their families pay about \$4 BILLION a year for out-of-pocket costs associated with treatment.²

patients in their homes by paying their mortgage or rent, 12% were used for transportation, 10% for utilities and 11% for other non-medical expenses.¹³ However, it is clear that the scale of this national problem is significantly underappreciated, and inadequate resources are available to support patients and families to effect large-scale improvement. More efforts are needed to assist the thousands of families who need meaningful assistance to counteract and prevent this debilitating side effect of cancer from occurring.

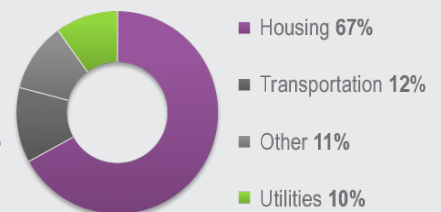
Furthermore, the need for interventions to alleviate CRFT is increasing in part because of a steady rise in

Lost Income Forces Families to Fall Behind on Daily Expenses¹³

72% of the families reported losing more than **50%** of their income since the time of diagnosis



Family Reach Assistance Covers:



cost-sharing for insurance plans.¹⁴ For example, the Kaiser Family Foundation report on Employer Health Benefits indicates that “premiums for family coverage have increased 20% since 2011 and 58% since 2006.” Other forms of cost-sharing such as deductibles, copayments, and coinsurance have also increased on average.¹⁴

Core Objectives of This White Paper

Summarize the nature and magnitude of the problem of CRFT, characterizing the scope and scale of the financial impact of cancer and the impact on patient outcomes

Describe the populations at increased risk for CRFT

Highlight potential directions to make a bigger impact on mitigating CRFT for families

Going forward, interventions to treat CRFT must be developed to help keep patients and their families in stable financial health, not just during the initial treatment but for subsequent treatments, as out-of-pocket costs for cancer recurrence can be up to three times greater than the out-of-pocket costs for direct medical care.¹⁵ CRFT interventions may help patients maintain a sense of normalcy during a life-changing health crisis and, in turn, improve adherence to recommended cancer care pathways to achieve optimal health outcomes.¹⁶

This white paper summarizes key literature on CRFT

to inform philanthropic donors, for-profit companies, nonprofit partners, government agencies and the general public about the scope of CRFT. The ultimate goal is to facilitate major change to combat CRFT through collaborative efforts so that no patient or family suffers material hardships, the inability to adhere to a prescribed treatment plan, or unintended negative clinical outcomes resulting from CRFT. This vision was recognized in 2016 by the White House's Cancer Moonshot initiative led by Vice President Joseph Biden.



Photo credit: Elise Amendola / AP

CANCER MOONSHOT

Vice President Joe Biden speaking at a Cancer Moonshot event in 2016 where Family Reach represented patients' voice in the struggle with cancer-related financial toxicity.

Cancer-Related Financial Toxicity is a Devastating Problem for Patients and Their Families

Pediatric Cancer Patients

CRFT can greatly affect families of pediatric cancer patients, as parents often find their employment and income disrupted when their child is treated for cancer. Not only can parents be burdened by high treatment costs; they also often reduce their working hours or discontinue employment altogether to cope with the stress of caring for their child with cancer.¹⁷ Families of pediatric cancer patients typically experience higher out-of-pocket costs (eg, travel, hotel, food) and longer duration of treatment because pediatric cancer treatment is not available in community oncology settings and protocols are generally more

Parents of Pediatric Patients Face Significant Income Loss¹⁸

56% of parents experienced some type of work disruption, with **15%** of them either quitting their jobs or being laid off as a result of their child's illness.

Among these families, the most commonly reported household material hardships were:



Food insecurity



Housing



Utilities

intense and longer than for adult cancer patients.⁵ Nearly one in three families are unable to meet their basic needs because of a pediatric cancer diagnosis.¹⁸ Although the economic impact of treatment costs and lost wages is often greatest during and immediately following the treatment period, it can extend well beyond, as parents attempt to re-establish their careers once treatment ends.¹⁷

There is limited research that describes the impact of CRFT on cancer outcomes for pediatric cancer patients and their families. Single studies have found that parents with more severe forms of CRFT also report serious psychological distress or strained parental relationships.⁵ Families of pediatric cancer patients who have received financial assistance from Family Reach for CRFT share stories that echo the problems highlighted in the literature.

Case Example: Gabriel

On August 7, 2015, just two days before hitting the field for senior year football practice, Gabriel was tackled with the news no teenager should ever have to hear: "You have leukemia." Diagnosed with



acute lymphocytic leukemia (ALL), Gabby faced countless rounds of chemotherapy. Living in upstate, rural Montana, Gabby and his single father Dean sought out the best medical option available by traveling from their home to Seattle Children's Hospital in Washington state. Dean, a recent widower, was adjusting to his new role as a single dad in addition to the new diagnosis. He took a leave from his blue-collar job and set out to save his son. As the medical bills and travel expenses accumulated, Gabby fought hard, far from the home he loves. He also worried if his father could keep their home in Montana.

Adult Cancer Patients

CRFT is also highly prevalent among families of adult cancer patients. A systematic review of 25 studies on the financial toxicity of cancer found that up to 73% of adult cancer survivors experience some level of CRFT.³ While in many cases CRFT is temporary and surmountable, a significant proportion of cancer patients experience more severe financial hardships that can have long-lasting effects. In a population-based survey of colon cancer patients in western Washington state, Shankaran and colleagues found that nearly 40% reported major financial hardships (debt, refinancing or selling primary home, $\geq 20\%$ decline in household income, loans from friends/family), often well after diagnosis and treatment had completed.¹⁹ Indeed,

The study found that adult cancer patients were 2.65 times more likely to file for bankruptcy than patients of a similar age without cancer.²²

This growing body of research suggests that higher levels of CRFT are associated with decreased quality of life, poorer treatment adherence and poorer survival for adult cancer patients.⁸ A survey study of patients diagnosed with cancer conducted by Zafar and colleagues found that 20% of patients take less prescription medication than was prescribed, 19% reported partially filling a prescription and 24% reported not filling the prescription altogether to defray treatment cost.²³ A similar study reported that 29% of patients said they skipped doctors' appointments, 38% post-

CRFT Brings Distress, Bankruptcy and Mortality



Up to **73%** of adult cancer patients experience some sort of CRFT³



Higher levels of CRFT are associated with decreased quality of life, poorer treatment adherence and poorer survival for adult cancer patients⁸



38% of adult cancer patients postponed or did not fill drug prescription to reduce costs²⁴



Adult cancer patients are **2.65 times more likely** to file for bankruptcy than patients of a similar age without cancer²²



Patients who filed for bankruptcy had a **79%** greater risk of early mortality than patients who did not⁹

a significant proportion of patients with cancer experience unrelenting debt as cancer treatment costs continue to accumulate over time.

About 1 out of every 300 US adults filed bankruptcy in 2016,^{20, 21} creating a ripple effect of unpaid debt throughout the economy. Ramsey and colleagues linked Washington state bankruptcy records to cancer registry and driver's license records to investigate the association between cancer diagnosis and bankruptcy.

poned or did not fill drug prescriptions, 34% skipped doses and 31% cut oral medications in half to reduce costs.²⁴ Another study found that patients who filed for bankruptcy had a 79% greater risk of early death than patients who did not file for bankruptcy.⁹ Using records from Family Reach's financial assistance program, we provide an example to illustrate the financial toll that cancer has on families as they experience income loss and long periods of treatment.



Case Example: Michael

Michael is a hardworking, loving 32-year-old father who lives with his wife, Leslie, and their three young children. In December of 2014, Michael was diagnosed with a rare form of non-Hodgkin lymphoma. Following a grueling and extensive treatment plan, Michael experienced a brief period of remission, sadly relapsing in early 2017. Due to the aggressive nature of Michael's disease, he required an even more intense protocol consisting of high doses of chemotherapy followed by a stem cell transplant. The frequency and length of Michael's care, as well as the extreme side effects of the treatment, left Michael unable to work for months at a time. His wife, Leslie, serves as not only his caretaker but also as full-time mother to their 6-year-old daughter and 3-year-old twins. Michael's relapse has taken a toll on this young family's financial wellbeing. With a drastic decrease in income, mounting out-of-pocket costs and increasing travel expenses to and from the hospital, Michael and Leslie have found themselves in over their heads, unable to pay their mortgage and utility bills.

Populations at Increased Risk for Cancer-Related Financial Toxicity

Several factors at the time of diagnosis influence a patient's vulnerability to CRFT, including pre-illness financial health, age of cancer patient or caregivers and insurance cost-sharing.^{3,5,6,25,26} Early and ongoing communication between the patient and the oncology team may lower a patient's risk of CRFT, even if they are at increased risk because of pre-diagnosis characteristics.^{8,27} Additional information about populations at increased risk for CRFT during cancer treatment is described below.

Increased Risk Among Patients and Families With Poorer Financial Health at Diagnosis

One of the patient groups most vulnerable to CRFT is families with poorer financial health before the cancer diagnosis.²⁶ Financial health comprises a multitude of factors including debt load, assets and income.²⁶ Lower income has been reported as a risk for CRFT in the literature on both adult and pediatric oncology. Survey research has laid the groundwork for developing hypotheses about CRFT and poor financial health at diagnosis.²⁶ For example, a survey study of families of pediatric cancer patients found significantly higher percentages of families with income $\leq 200\%$ of the federal poverty level (FPL) who reported income lost due to work disruptions ($P=0.02$), food insecurity ($P<0.001$), energy insecurity ($P=0.001$), housing insecurity ($P=0.05$) and phone disconnected for non-payment ($P<0.001$) compared to families with income $>200\%$ FPL.¹⁸ Another study of pediatric cancer patients undergoing stem cell transplant linked survey data to medical record data and found risk for graft-vs-host-disease within 180 day of transplant was more than 3X higher among children of families with reported personal income $\leq 200\%$ FPL compared to children from families with reported income $>200\%$ FPL ($P=0.004$).²⁸ Graft-vs-host disease is a serious complication of cancer treatment and the association with poverty level may

be explained by families having limited resources to support adherence to complicated treatment schedules, including housing with adequate refrigeration for medication, healthy food options for administering medication or transportation to receive treatment.²⁸

Low-Income Families Experience Poorer Health Outcomes²⁸

Graft-vs-host-disease within 180 day of transplant was more than **3X** higher among children of families with reported personal income $\leq 200\%$ FPL compared to children from families with reported income $>200\%$ FPL ($P=0.004$).

Children from high-poverty areas relapse sooner than children in low-poverty areas.²⁹



In a subsequent study, Bona and colleagues reported on socioeconomic status as a predictor of time to relapse (a known prognostic factor, with earlier relapses being harder to salvage) and overall survival in children with ALL. In this analysis, 92% of relapses in children living in high-poverty areas vs 48% among children living in low-poverty areas occurred within 36 months of achieving complete remission ($P=0.008$).²⁹ Children living in high-poverty areas experienced a 5-year overall survival of 85% vs 92% in children living in low-poverty areas ($P=0.02$). These findings suggest that disparities in childhood cancer outcomes exist based on poverty level, despite uniform treatment of the disease.²⁹

Increased Risk Among Younger Adult Patients and Families

Younger adult patients are particularly at risk for extensive treatment costs. Indeed, younger adult patients recently diagnosed with cancer have two to five times higher rates of bankruptcy compared with elderly patients ≥ 65 years with cancer.²² Ramsey et al offered an explanation for this age difference: (1) young adults often have a high debt-to-income ratio due to student loans, purchasing homes, or starting new businesses; (2) older working-age patients suffer loss of income and loss of employer-sponsored insurance if unable to work; and (3) elderly patients, on the other hand, generally have Social Security benefits, Medicare insurance coverage and more assets in general, thus making the economic hardship less pronounced.²² Another study found that two-thirds of patients between the ages of 25 and 64 stopped working full time during treatment.²⁴ In addition, despite advancements made with the Affordable Care Act, younger adults aged 27 or older are not eligible for insurance coverage under their parents' plan, which may increase their risk for CRFT if access to affordable health insurance coverage is not avail-

Younger adult patients recently diagnosed with cancer have 2 to 5 times higher rates of bankruptcy compared with elderly patients ≥ 65 years with cancer.²²

able through their employer or state health insurance exchange.¹⁶

Increased Risk Among Patients With High Cost-Sharing Insurance Plans

Importantly, the increased risk for CRFT persists, even after controlling for insurance, suggesting that at-risk subgroups will experience financial concerns despite health insurance coverage.²⁵ It is also worthy to note that the financial hardships faced by cancer patients

and their families are not limited to those who are uninsured. The insured receiving cancer therapy are also very vulnerable. In a survey of 254 insured cancer patients, 42% reported a significant or catastrophic financial burden of increasing out-of-pocket costs, including expenses, travel costs and insurance premiums.²³ To compensate for this spending, 46% of insured patients reduced spending on food and clothing, while another 46% resorted to using long-term savings to defray their out-of-pocket expenses.²³

Selecting an optimal insurance plan, one that decreases out-of-pocket costs without lowering coverage, is a complicated process. Patients with lower literacy and numeracy skill need assistance to

Insured Patients Also Face CRFT²³

Of these patients:

42% of insured cancer patients reported a significant or catastrophic financial burden.



make informed decisions about the best health plan for their situation given access to in-network providers, etc.^{10,30} Lower-income patients may be attracted to plans with lower monthly premiums but then learn that they have to pay high out-of-pocket costs for their cancer care. A Kaiser Family Foundation survey found that only 51% of respondents could correctly calculate the out-of-pocket cost for a hospital stay involving a deductible and copay, and only 16% could determine the cost of an out-of-network laboratory test when the insurance company capped the allowable charge.¹⁰ Assisting patients with financial navigation is a patient-centered approach to healthcare and can mitigate CRFT. Furthermore, optimizing insurance

plans for patients will likely result in financial benefit for the hospital through improved revenue streams and lower provision of free care.³¹

Improved Communication About the Costs of Cancer Care May Lower the Risk for Financial Toxicity

Underlying the experience of CRFT in adult cancer patients is a lack of communication between the patient, physicians and clinic staff about the financial aspects of cancer care. Despite many experts and professional societies such as the American Society for Clinical Oncology (ASCO) calling for increased communication with patients about cancer care costs, there are still barriers to these discussions at the patient level (embarrassment, fear of receiving suboptimal care) and physician level (lack of time, lack of expertise).^{8,11,27} Understandably, however, most families (57%) do not want to consider out-of-pocket costs when selecting treatment, and many (42%) do not want their physicians to consider these costs out of fear of limiting potentially life-saving treatment options presented by the care team.²³

Despite this patient care guideline, numerous patient surveys show that physicians are not speaking with patients about the cost of cancer treatment.^{8,24} A survey of breast cancer patients found that only 14% reported having discussed cost with their physician, even though 94% wanted physicians to discuss the cost of cancer treatment with them.⁸ Strategies that empower patients to discuss the cost of treatment with hospital staff could provide information they need to manage their treatment costs and non-medical expenses before they get behind in payments.⁸

Barriers to Discussing the Cost of Cancer

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Only **14%** of breast cancer patients reported having discussed cost with their physician, even though **94%** wanted physicians to discuss the cost of cancer treatment with them.⁸

Conclusions

The 1.6 million patients and families in the US who learn of a cancer diagnosis each year face a multitude of physical and emotional challenges as they attempt to focus on treatment, recovery and survival. As new research and groundbreaking therapies continue to provide ultimate hope of better patient outcomes, the often-overlooked burden of CRFT unfortunately lies hidden in plain sight. In a country and an economy known for resolve, innovation and social awareness, the problem of CRFT simply should not perpetuate. As emerging studies have shown, not only can CRFT wreak havoc on a patient and family's basic well-being, but it can actually impair chances for cancer survival and recovery. With coordinated and collective actions from a powerful ecosystem of for-profit, nonprofit and public sector stakeholders, cancer patients and their

families can reap the benefits of billions of dollars of monumental research and development, and the passionate efforts of thousands of healthcare professionals, regardless of their financial condition. Nationally, nonprofit organizations dedicated to addressing the large unmet needs of patients experiencing CRFT (e.g. Family Reach, CancerCare, Patient Advocacy Foundation) have made a noticeable, yet initially incremental impact over the last two decades. Our collective actions need to create and deploy new financial treatment interventions and systematic models of change to prevent and reduce this pervasive condition. Through collaboration with a range of partners on a large scale we can offer patients and families their greatest chance for positive outcomes and survival.

Key Takeaways

1 Income loss is common among adult cancer patients and families of children with cancer and can lead to the inability to afford daily living expenses

Nonprofit organizations like Family Reach have stepped in to pay mortgages, utility bills, car payments and more. Paying bills can mitigate CRFT, but this approach is unsustainable. A broader community effort from housing, utility, transportation, food and banking industries is needed to delay or alleviate these expenses for patients in active treatment.

2 A majority of adult cancer patients will experience CRFT, leading to non-adherence to treatment and a lower chance of survival

A multicomponent approach to financial interventions will play a key role in addressing CRFT. Financial navigation, financial planning, education and financial assistance provided to patients early and throughout their cancer journey will likely have the greatest impact on reducing financial barriers to treatment adherence and improving disease outcomes.

3 Broad support from the private sector is needed to develop solutions for CRFT

Filling gaps in research that better demonstrates the economic impact of CRFT, bankruptcy and non-adherence to treatment is a priority. Roadmaps for solving the problem of CRFT, like this white paper, generate discussion on the topic and guide future research to fill the gaps.

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