Financial burdens and challenges experienced by geographically remote families during pediatric cancer treatment: A qualitative analysis

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Abstract

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ABSTRACT

Introduction: Children with cancer and their families often experience financial toxicity, defined as the adverse financial effects resulting from cancer care. Limited research has explored the financial experiences of families from geographically remote locations, who may be at increased risk for disproportionate negative effects.

Materials and Methods: Using a phenomenological approach, we conducted 13 semi-structured interviews with caregivers of children with cancer with a permanent residence located greater than 60 minutes of travel time from their treating center. We performed a thematic analysis of interview transcripts focused on elucidating how elements of financial toxicity manifested and subsequently impacted patients and families.

Results: We identified five general themes; four related to separate constructs of financial toxicity and one related to coping behaviors in response to financial challenges. We identified several exacerbating and ameliorating factors salient to the development of financial toxicity. Specifically, geographic distance to care often provoked or exacerbated financial toxicity.

Conclusion: Geographically distant families of pediatric patients with cancer experience a wide range of financial toxicity and caregiving challenges throughout treatment, and families perceive distance to care as an important provoking factor. Interventions are needed to mitigate the development and effects of financial toxicity for

families of children with cancer, and greater attention should be given to examining financial toxicity specifically among geographically distant families.

INTRODUCTION

Children with cancer and their families often face substantial treatment-associated challenges in several domains, including financial, material, occupational, and psychosocial, with increasing attention being given to understanding and addressing how families navigate these burdens.[1–6] However, limited research in pediatric oncology has explored such challenges specifically among families from geographically remote or rural locations during therapy.[7–9] Geographic distance to care and/or rural residence have been associated with inferior survival from various types of pediatric cancers,[10–13] providing impetus to better understand such families' experiences and consider possible mechanisms driving disparities in outcomes. Furthermore, geographically remote populations comprise a significant proportion of patients treated at pediatric cancer centers in the US. An estimated 17% of the pediatric population resides greater than 60 minutes of travel time from access to any pediatric oncology care[14] and 39% of US children live greater than 60 minutes from a facility able to provide comprehensive cancer treatment including hematopoietic stem cell transplant,[15] highlighting the potential impact of improving this population's experiences.

Investigations into the experiences of geographically distant patients and families during cancer treatment raise concern for an elevated risk of experiencing adverse financial consequences related to cancer care—also termed *financial toxicity.*[16,17] A qualitative thematic analysis of a relatively homogeneous sample of 16 families of children with leukemia identified several obstacles, including burdensome travel times to appointments and perceived difficulty associated with accessing expedient emergency care in community hospitals.[9] However, while not a primary focus of this analysis, families often also reported increased out-of-pocket expenses and extra caregiving requirements.[9] A cross-sectional survey study of 254 caregivers also found that geographically distant families could experience heightened stress related to finances, measured by a non-validated visual analog scale.[8] These investigators also demonstrated that children in such families missed a greater number of school days and were more likely to be held back a year or more.[7] However, we lack a comprehensive understanding of how individual elements of financial toxicity develop and manifest in geographically remote families, how they cope with these challenges, and how patients and families are ultimately impacted. Diverse family perspectives are critical to understanding modifiable targets to improve their care.[18] In settings with limited existing literature, qualitative methods can effectively capture complex lived experiences.[19,20]

We sought to explore how the geographic distance between a patient's permanent residence and their treatment center shapes families' experiences with financial toxicity within the context of caregiving during initial cancer treatment.

METHODS

Study setting.

The study took place at Seattle Children's Hospital (SCH), a freestanding quaternary children's hospital that cares for approximately 400 patients newly diagnosed with cancer annually. Patients treated at SCH for initial first-line cancer therapy largely reside in Washington State, Alaska, Northern Idaho, and Western Montana. Many patients treated at this center report a permanent residence greater than 60 minutes of travel time from the hospital, a cutoff we used to define families as "geographically distant" to their treating center. Geographically distant patients with cancer treated at SCH are universally offered local accommodations free of charge; however, families may also choose to remain in their own community (i.e., their permanent residence) if deemed appropriate by their oncology team, provided they can access basic pediatric emergency care close to their home and travel to SCH regularly for subspecialty treatment. Families are also provided with the option to pursue alternative local accommodation options within 60 minutes of travel time to SCH, including private rentals. The costs of non-institutional housing may not be furnished by our institution. Some children, such as those receiving a hematopoietic stem cell transplant or a profoundly myelosuppressive treatment regimen (including acute myeloid leukemia, high-risk neuroblastoma, relapsed acute lymphoblastic leukemia, and young infant brain tumor treatment), are mandated to relocate to within 60 minutes of SCH for the large majority of treatment.

Participants and recruitment.

We applied purposive sampling to recruit a diverse sample of caregivers across cancer type, location of residence, language of care, insurance status, as well as race and ethnicity. Caregivers of pediatric patients with cancer undergoing myelosuppressive chemotherapy were identified via an electronic health record (EHR) list containing all patients with cancer treated at our institution diagnosed from 2021-2023. Caregivers were eligible for inclusion if: (1) they had a permanent residence greater than 60 minutes of travel time from SCH, (2) they were an adult legal guardian of a child with cancer <18 years old at enrollment, and (3) their child was being treated at SCH for a first cancer diagnosis (3-18 months prior). Caregivers with a permanent address outside our institution’s typical geographic catchment area—Washington State, Alaska, Idaho, and Montana—were excluded, along with caregivers of children who specifically traveled to our institution to participate in a Phase 1 clinical trial or receive hematopoietic stem cell transplant after having received primary oncology care at a different institution.

We approached eligible caregivers in-person (clinic or inpatient unit), by telephone, or by mail. Informed consent was obtained prior to each interview. Caregivers were recruited and enrolled until thematic saturation was achieved. A research investigator trained in pediatric oncology and qualitative data collection conducted all interviews, using a standardized interview guide. Interviews with caregivers speaking a language other than English were conducted with real time interpretation. We identified and approached 16 caregivers of patients for study participation, 13 (81%) of whom agreed to participate and completed a semi-structured interview. Of these, 12 (92%) completed the demographic survey following the interview. Participants were provided a $50 gift card after completion of the interview to compensate for their time and effort. All study procedures were approved by and performed in accordance with the SCH institutional review board.

Interview procedure.

In-depth, semi-structured interviews of caregivers were performed in person, by telephone, or secure videoconferencing technology and lasted approximately one hour each. A phenomenological approach was chosen to explore caregivers' lived experiences and understand how such experiences influenced behavior.[19] The interview guide consisted of open-ended questions with probes, asked in plain language to explore salient factors related to individual aspects of financial toxicity. Questions were derived from existing research among in children and adults with cancer,[17,21,22] focusing on how geographic distance to care influenced the manifestation of financial challenges, and how these effects may have impacted their family's well-being. The interview guide was iteratively revised to further investigate new topic areas that emerged from our concurrent data analysis. Interviews were audio-recorded and transcribed verbatim by an independent transcriptionist.

Demographic survey.

Following interviews, caregivers completed a demographic survey composed of basic household and demographic questions (Supplemental Table 1). Additional questions related to the home environment and transportation were adapted from the WE CARE Survey instrument, a validated self-report tool to capture social determinants of health and unmet social needs.[23,24] Basic patient demographic information was obtained from administrative data in the electronic health record.

Data analysis.

We conducted thematic analysis of the interview transcripts following the approach outlined by Miles, Huberman, and Saldaña.[23] Transcripts were read in entirety by at least two investigators independently. We used an inductive, constant comparison approach to code the transcripts. First, three investigators created a set of tentative codes based on three transcripts. Using an iterative process, the team met regularly to refine the codebook by adding, removing, and revising codes to address inter-rater agreements and to compare new and existing data. Next, we identified themes from the codes by first reviewing excerpts within each code and identifying themes based on the content. The interrelationships across and within themes were analyzed, resulting in a collection of candidate themes. Next, candidate themes were reviewed by the research team, and further refined to ensure excerpts within themes cohered and each final theme was distinct and unique. All data were analyzed using Dedoose qualitative coding software, version 9.0.86.

RESULTS

Caregiver, family, and patient characteristics.

Results are shown in Table 1. Participants were predominantly mothers (85%) and >40 years of age (58%). Half of caregivers reported having a college degree (50%). All families reported average travel times to the hospital of 60 minutes or greater. The proportions of families reporting travel time of 60-120 minutes, 2-4 hours, and 4 hours or more were 25%, 25%, and 50%, respectively. Patient characteristics, shown in Table 2, were notable for variation in demographic characteristics as well as cancer type and transplant status.

Theoretical framework.

Distinct aspects of financial toxicity emerged from the qualitative data and were organized into five principal themes, shown in Table 3 with associated codes and illustrative quotes. Four themes related specifically to individual constructs of financial toxicity, and one theme encompassed reactionary behaviors to financial challenges that often mediated the overall impact on the patient and family, termed *coping behaviors*. Key ameliorating and exacerbating factors were also identified in relation to the five principal themes (Table 4), and could occur at the patient-, family-, community-, and medical system-level. Notably, geographical distance to care had considerable impact on many aspects of financial toxicity. The relationships between individual financial toxicity themes, as well as their effects on patients and families, are summarized in the theoretical framework presented in Figure 1. Ameliorating and exacerbating factors related to financial toxicity themes, with accompanying exemplar quotes, are shown in Table 4.

Theme 1: Direct costs

Families almost universally reported increased out-of-pocket spending following their child's diagnosis, referred to as *direct costs*. Common sources of direct costs included transportation, caregiving for patients or other family members, food, and for families who temporarily relocated to closer proximity to our institution, simultaneously managing two households. For families who elected to reside outside of institution-furnished housing, additional costs from rent and utilities were usually far greater compared with baseline costs in their home community. Virtually all families noted increased expenditures associated with transportation, with costs of round-trip travel ranging from $20-$40 to over $100 in fuel. For families residing in very remote locations, airfare or ferry rides were additive costs. Several families also shared related increases in vehicular maintenance or insurance costs. Regarding food, many families lamented local cost of living, while also feeling that their child's illness often necessitated purchasing more expensive options, either due to changes in patient tastes or a limited ability to leave the bedside to cook or shop for groceries.

The process of relocation to closer proximity relative to the treatment center presented additional direct costs, with families often paying out-of-pocket to purchase new items (cheaper or more accessible than transporting them from home) or paying for accommodations before financial resources were made available. In general, families also noted minor costs related to medical care, such as over the counter medications or medical equipment. Major medical bills were almost always covered by insurance or uncompensated care.

Theme 2: Indirect costs.

Indirect costs were defined as lost or reduced household income related to opportunity costs. Changes in employment in response to increased caregiving needs drove the vast majority of increased indirect costs. Two-thirds of families reported at least one caregiver in the household losing or quitting their job because of their child's cancer. Other caregivers were able to maintain their employment/income but reduced working hours, changed job duties, or forewent career advancement to do so. While many families used medical leave and/or unemployment resources, income from these sources was usually a fraction of families' baseline income and did not last the duration of treatment. Other time was spent navigating the healthcare system, particularly insurance and billing, though these activities did not seem to have a direct role in employment changes. Three families—two from out-of-state—estimated time spent navigating the system to exceed dozens of hours.

Extended travel distance and increased caregiving requirements were frequently cited as the primary factors forcing employment changes and subsequent income loss. Longer treatment durations and greater baseline needs from non-patient household members (i.e., siblings or elderly adults) were also exacerbating factors. Many participants shared factors potentially protective against higher indirect costs, which included the presence of multiple caregivers in the home and flexible or remote employment options.

Theme 3: New material hardship.

Material hardship, defined as difficulty affording or accessing basic necessities,[21,26] developed during treatment after families incurred high direct and/or indirect costs. New material hardship emerged as a separate theme because the extent of costs that families reported was not always related to the development of material hardship; that is, not all families with the greater costs necessarily reported resultant new material hardship. However, certain trends emerged. In particular, loss of employment, especially when combined existing or new out-of-pocket costs, resulted in new material hardship for some families. In comparison, no family that was able to maintain employment during their child's treatment reported new material hardship.

In addition to income losses and high direct costs, material hardship was exacerbated by lower baseline wealth or savings, having fewer support systems, and longer duration of treatment. Notably, material hardship in relation to medical bills was not reported by any caregivers. Ameliorating factors included maintenance of employment, greater baseline wealth, and resources provided by existing support systems, the hospital, and community organizations. Geographic distance to care affected material hardship at many of these levels, usually as an exacerbating factor. Geographically distant families—particularly those at greatest distance—frequently reported sustained income losses, incurred greater direct costs, and experienced separation from their support systems. The limited availability of resources and support seemed to be a challenge regardless of distance from care. However, families crossing state lines often found that they were ineligible for some types of financial support that would have otherwise been available to them had they been residing in-state.

Theme 4: Psychological distress due to financial changes.

Most families reported elevated degrees of psychological distress related to finances, which developed following their child's diagnosis. Psychological financial distress emerged as a downstream effect of increased costs (direct and/or indirect), with or without new material hardship. However, there was considerable heterogeneity among families' reports of psychological distress, which did not always correspond closely to the degrees of experiences with financial costs or material hardship. Financial distress was frequently associated with coping behaviors (Theme 5), particularly when severe, and often cited as negatively impacting the patient and/or family.

Several factors were cited as worsening psychological financial distress. Families who reported new material hardship also frequently discussed experiencing elevated distress. General unfamiliarity with resources and limited use were also exacerbating factors. Some families explained that they had no prior experiences with financial stressors until their child's diagnosis, and this lack of experience potentially increased their overall distress. Some families expressed a feeling of isolation from support systems—extended family, friends, and community organizations—in the context of their financial distress, specifically with regard to being less able to mobilize these systems to support their needs in response to financial stressors. Threatened costs that were never actualized, such as medical bills that were eventually covered by insurance, could also be highly distressing. A few families remarked that the hospital's mobile health application posted a bill on its welcome page, a constant reminder of financial stressors even with the recognition that the full amount would not need to be paid. Multiple families reported feelings of pride or guilt in seeking and utilizing resources, despite great need, sometimes worsening distress. Common protective factors against psychological financial distress included existing familiarity with accessing resources and a willingness to use them, as well as connectedness to support systems in the community and hospital. The social work team was instrumental for some families, not only to identify resources but to serve as a support system that caregivers felt they could rely on if needed. Families with greater geographic distance to care often reported psychological distress, not only due to increased costs, but also a larger sense of isolation from support systems hindering their ability to resolve these stressors.

Theme 5: Financial coping behaviors.

We defined *financial coping behaviors* as actions used by families to address financial toxicity constructs in ways that differed from their typical behavior. Most families exhibited coping behaviors, but these varied considerably by family. We observed relationships between coping behaviors and all financial toxicity themes, most frequently as a response to financial distress and material hardship.

Many families limited travel to and from the hospital to save money. Multiple caregivers, especially those with greater travel distances or geographic barriers, refrained from visiting their permanent residence or other family members for months at a time. In response to direct or indirect costs, a few families reported selling assets to create financial liquidity, or making big purchases for their child’s care to avoid other potential financial burdens. Some families noted changes in food purchasing habits, such as foregoing certain foods or buying exclusively cheaper, less healthy food for their child. Regarding employment, a few families reported “job lock”, a phenomenon of remaining in a job for the primary reason of maintaining health insurance coverage or other benefits. Caregiving for siblings or other adults in the household was also frequently affected. Sometimes, children were placed in the care of older siblings or resided alone in the original home for extended lengths of time to avoid childcare costs.

Specific behaviors could have negative or positive downstream effects on the patient and family, and could also moderate subsequent financial toxicity. For example, severely restricting travel to a permanent residence could have negative psychosocial impact for patients as well as family members, and potentially affect a child's medical care. Yet, this strategy could also reduce direct costs related to transportation. In contrast, crowdfunding ventures, although psychologically uncomfortable for a few families, could also help raise money to avert material hardship and reduce psychological financial distress. Often, coping behaviors with positive effects could mitigate aspects of financial toxicity or reduce patient and family impact. In contrast, maladaptive behaviors with negative effects, as also described above, could worsen financial situations or adversely impact the patient or other family members.

Provoking factors for greater coping behaviors often reflected what we observed with individual financial toxicity elements. The perceived availability and accessibility of support systems seemed to have a strong influence, with families who reported feeling isolated or unsupported being more likely to engage in coping behaviors, particularly those with maladaptive effects. Similarly, caregivers expressed feelings of support from extended family, friends, their community, and the hospital as reducing their propensity or need for coping behaviors.

Some families reported having to overcome a sense of pride or social norms to find ways to cope with their financial situation, which was distressing in itself. Examples included "advertising" their situation for crowdfunding ventures to raise money to cover new or ongoing costs, relying on previously professional relationships for personal support (such as paying student loans or subsidizing rent), and cleaning and reusing items previously discarded by others.

DISCUSSION

This thematic analysis describes specific elements of treatment-related financial toxicity among a demographically diverse sample of families of children with cancer with a permanent residence geographically distant from their treatment center. Our results highlight how financial toxicity may manifest by applying caregivers' lived experiences to hypothesize the relationships and mechanisms underlying individual financial toxicity constructs. Overall, we observed several unmet needs among this population across the trajectory of cancer treatment, related to out-of-pocket costs, lost income, new material hardship, and increased financial distress. Critically, these elements of financial toxicity demonstrated negative impacts on family members and their ability to care for patients, in conjunction with financial coping behaviors that provided insight into families' approaches to the challenges of cancer care. Finally, we identified ameliorating and exacerbating factors salient to financial toxicity across the trajectory of cancer care, specifically exploring families' perceptions of how they were impacted in the context of their geographic distance to care. Ameliorating and exacerbating factors, if modifiable, may be targeted in future initiatives to mitigate financial toxicity for other families.

Our findings provide novel insights specifically into the financial challenges faced by geographically distant families during a child's cancer care. The diverse perspectives provided by our caregiver sample also build upon the previous report of Walling and colleagues in their qualitative examination of the general challenges during pediatric cancer care.[9] This analysis of relatively homogeneous families of children with leukemia focused largely on care challenges in local community hospitals and transportation difficulties, though also acknowledged financial challenges as significant and stressful. Our findings provide perspectives from a wider range of families with varying cancer types, geographic situations, and racial and ethnic backgrounds to complement this work, as well as a deeper focus on the mechanisms of financial toxicity and individual ameliorating and exacerbating factors compared with prior survey-based investigations.[7,8] Our study also examines the role of temporary relocation to institutionally-provided housing, a practice that may vary across institutions. With specific regard to relocation, we explored possible positive and negative financial impacts should be considerations for families who have an option for temporary geographic location available to them.

Although this analysis was limited to families living greater than 60 minutes from their treatment center, variation in access between home and hospital—largely pertaining to travel distance—had marked impact on families' financial experiences and decision-making throughout the trajectory of cancer care. Greater distance and its associated barriers were frequently observed along with exacerbating factors for financial toxicity across all themes. In particular, geographic barriers added complexity to caregiving for patients and other family members, an integral consideration for maintaining a stable income following diagnosis. Increasing geographic distance was also associated with progressively greater financial burdens related to transportation and housing. Caregivers from greater distances also felt disconnected from their traditional support systems such as family, friends, and spiritual organizations. Diminished support from such systems left some caregivers more vulnerable to experiencing greater financial stress and partaking in coping behaviors with maladaptive effects. Further investigation will be needed to compare these financial experiences to those of more geographically proximal families, and subsequently develop targeted interventions to reduce financial toxicity through modifiable factors. The additional challenges that geographically distant families face will require special attention to ensure equitable solutions for this critical group.

Our findings are generally consistent with prior frameworks of financial toxicity in pediatric oncology, with important differences. Similar to the conceptual models proposed by Salsman et al. and Santacroce and Kneipp,[17,21] four distinct themes of financial toxicity emerged from our analysis: direct costs, indirect costs, material hardship, and financial distress. Similarly, new material hardship and distress tended to be downstream effects of financial costs, and we also found coping behaviors to be important downstream effects of all financial toxicity constructs, both as a reflection of overall family impact, but also a possible mediator of patient and family outcomes. However, while Santacroce and Kneipp conceptualized financial distress as a downstream effect of certain coping behaviors, our model favors financial distress as more proximal, a direct result of costs and/or material hardship and impactful precedent to maladaptive coping behaviors. Intervening on modifiable factors to ameliorate financial distress itself could be considered to reduce maladaptive coping behaviors or redirect coping behaviors to be more positive/adaptive.

Financial coping behaviors often highlighted particularly salient elements of financial toxicity for families and also provided insight into overall patient and family impact. We also observed instances of coping behaviors having conflicting effects on different financial toxicity themes—for example, driving without a license to save money could alleviate material hardship, but contribute to increased financial distress. Further investigation is warranted to understand how coping behaviors may develop from various financial toxicity elements, as well as how such behaviors may be guided to be more adaptive in nature, thus reducing future financial toxicity. Studies of interventions to mitigate financial toxicity could use coping behaviors both as an endpoint to determine their success, or interventions themselves could be designed to encourage coping behaviors to be adaptive, rather than maladaptive, to reduce subsequent financial toxicity.

Our qualitative analysis has several limitations. First, while including a diverse sample of caregivers—including those with a preferred language of care other than English—we may not have achieved thematic saturation for narrow subsets of cancer types, family geographies, or other factors. Our interviews with families ranged from 3-18 months following an initial cancer diagnosis; interviews further from cancer diagnosis could be impacted by recall bias, where families off therapy may not have accurately recalled every aspect of financial toxicity they experienced. Similarly, interviews conducted earlier relative to diagnosis may not have captured the full financial challenges that a family had yet to face later in treatment or early survivorship. Next, while our study results make inferences related to geographic distance to care, quantitative comparisons will be necessary to measure associations and make stronger conclusions. Finally, we conducted this investigation in a setting where temporary relocation to the institution’s close proximity is generally encouraged as a common practice; the distinct financial challenges and benefits that we report related to relocation may not reflect families' experiences at different institutions with alternative approaches to relocation during cancer treatment.

Future investigation in diverse cohorts will be critical to further evaluate financial toxicity among geographically distant families, devise quantitative measurement tools of important constructs, determine its contributions to pediatric cancer disparities, and develop targeted interventions to reduce patient and family impact. In the interim, our findings suggest that careful screening and resources should be applied to patients and families during cancer treatment, particularly those traveling great distances for care.

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Table 1: Caregiver and family characteristics (N=13).

Characteristic	**N***	**%**
Relation to patient		
Mother	11	84.6%
Father	2	15.4%
Other	0	0.0%
Age		
18-30	0	0.0%
30-40	5	41.7%
40-50	6	50.0%
50+	1	8.3%
Race and ethnicity		
American Indian or Alaska Native	2	16.7%
Asian or Pacific Islander	2	16.7%
Black/African American	0	0.0%
Latino/Hispanic	1	8.3%
Two or more races	0	0.0%
White	4	33.3%
Other/no answer	1	8.3%
Education		
Less than high school	2	16.7%
High school graduate or some college	3	25.0%
College graduate (4-year)	5	41.7%
Graduate degree	1	8.3%
Employed caregivers at time of diagnosis		
None	2	16.7%
1	2	16.7%
2 or more	7	58.3%
Income		
No answer	5	41.7%
<$50,000	2	16.7%
$50,000-99,999	4	33.3%
≥$100,000	1	8.3%
Household size		
2-4	5	41.7%
5-6	5	41.7%
7 or more	1	8.3%
Number of other children in household		
None	2	16.7%
1-2	8	66.7%
3 or more	1	8.3%
Number of adults in household requiring caregiving		
None	9	75.0%
One or more	2	16.7%
Housing type		
House - own	7	58.3%
House - rent	2	16.7%
Apartment	1	8.3%
Temporary housing or shelter	1	8.3%
Travel time from permanent home to hospital		
0-29 minutes	1	8.3%
30-59 minutes	0	0.0%

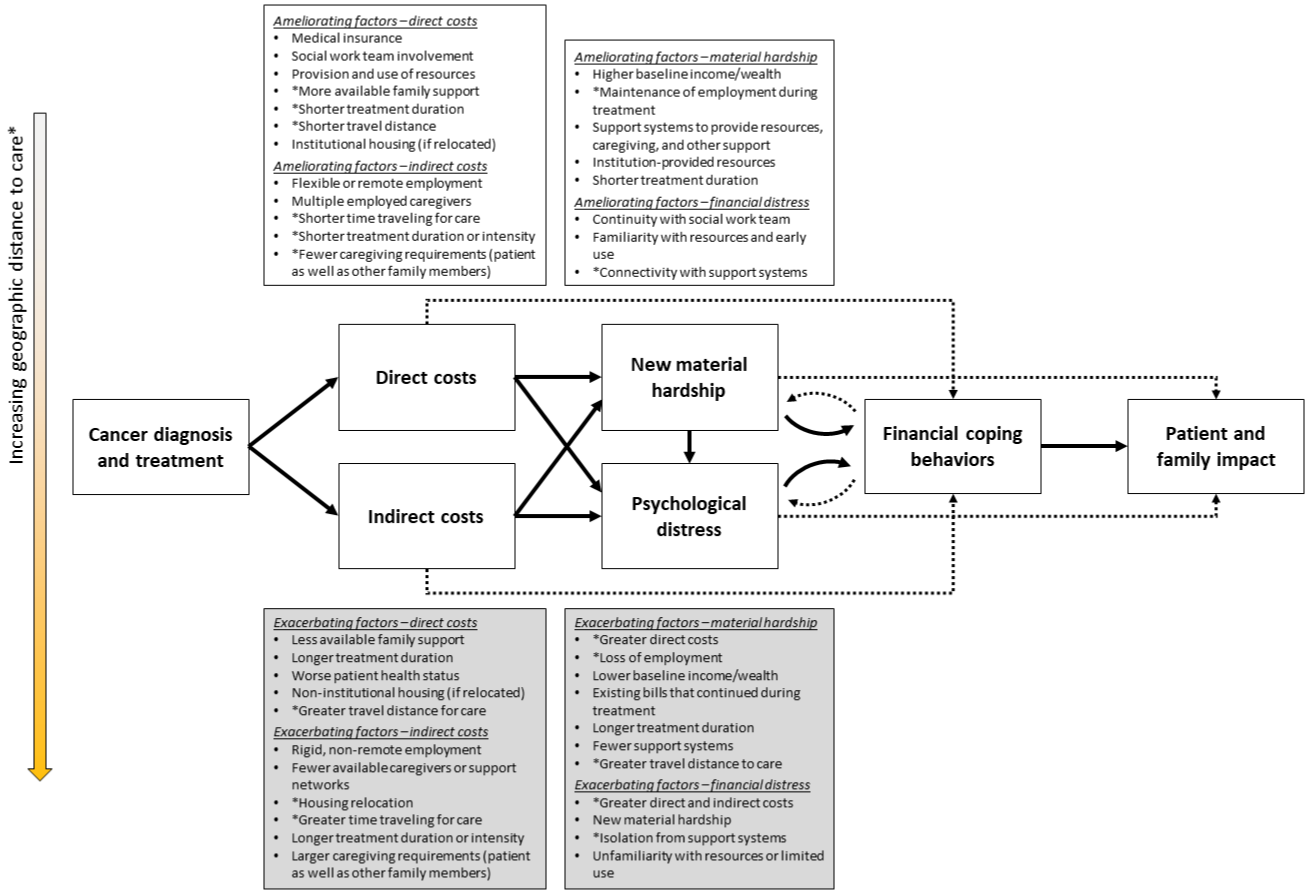
1-1.99 hours	2	16.7%
2-3.99 hours	3	25.0%
4 hours or greater	5	41.7%
Transportation type		
Private vehicle	9	75.0%
Other	2	16.7%
Number of vehicles the household has access to		
1	2	16.7%
2	7	58.3%
3 or more	2	16.7%

*The demographic survey was completed by 12 of 13 participants. One participant only partially completed the demographic survey; however, relation to patient was confirmed in all 13 instances.

Table 2: Patient demographic and disease characteristics (N=13).

Characteristic	**N**	**%**
Sex		
Female	5	38.5%
Male	8	61.5%
Age at diagnosis		
0-4.99 years	4	30.8%
5-9.99 years	2	15.4%
10-14.99 years	5	38.5%
15-17.99 years	2	15.4%
Race and ethnicity		
American Indian or Alaska Native	2	15.4%
Asian or Pacific Islander	2	15.4%
Black/African American	0	0.0%
Latino/Hispanic	3	23.1%
Two or more races	1	7.7%
White	5	38.5%
Cancer type		
Leukemia	5	38.5%
Lymphoma	2	15.4%
Solid organ tumor	4	30.8%
Brain tumor	2	15.4%
Transplant status		
Allogeneic	1	7.7%
Autologous	2	15.4%
None	10	76.9%

Figure 1



A conceptual framework of financial toxicity among geographically distant families of children with cancer, over the course of treatment, with ameliorating and exacerbating factors. Solid lines denote the dominant pathways for the development of financial toxicity among families, whereas dotted lines denote alternative pathways. White boxes at the top summarize sources of ameliorating factors, and gray boxes at the bottom of the figure list exacerbating factors. *Some ameliorating and exacerbating factors were impacted by geographic distance to care, potentially increasing the risks of financial toxicity and/or its effects with greater distances.

Table 3: Principal themes and associated codes, with typical exemplars.

Theme 1: Direct costs	
• Transportation/travel • Food • Caregiving • Housing/accommodations (especially if relocated) • Maintenance of two households (if relocated)	Mother of a child with leukemia/lymphoma: *“We were also having to take care of two houses. So we were having to financially make sure that our mortgage and our food was stocked and the bills are paid here at our home for our kids, and simultaneously having to do the same thing where we were at… And so it doubled, it was difficult.”* Mother of a child with a solid tumor: *“We were in here for 30 days. I finally got [patient] to eat some of the stuff from the cafeteria, but she just was really picking at it and just didn't want it. But when I finally caved in and got her a pizza, she ate half of it. It worked out. I got her to eat. But food is expensive.”*
Theme 2: Indirect costs	
• Loss of employment or income • Reductions in employment or income	Mother of a child with leukemia/lymphoma: *“I took a leave of absence from work. There was no way I was going to be able to work and live in Seattle, so I took a leave of absence.”* Father of a child with leukemia/lymphoma: *“I worked at this place for 10 years, and I used to think that my loyalty and my commitment and consistency, everything I thought that was valued there, just seemed to not be the way I thought it was. And to the point where letting me go as an employee, it almost seemed like it was too easy for them. Obviously, that impacted us financially because well that's thousands of dollars a month that we just lose like that.”*
Theme 3: New material hardship	
• Driven by direct costs • Driven by indirect costs • Housing and utilities in permanent residence • Housing and utilities in temporary relocated residence • Daily food • Transportation	Mother of a child with a solid tumor: *“Just recently I had a $1,100 light bill and they were sending me shut off notices… You only have so many resources out there that can help you. …But from living on unemployment, and then from unemployment to nothing… I was buying food. And a lot of times I made sure that [patient] was always fed… So, I'm like, we need food before we need, we had to put the bills aside…because, well, what else can we do?”*
Theme 4: Psychological distress due to financial changes	
• Triggered by costs, material hardship • Sentiments of pride or guilt • Strongly associated with coping behaviors	Father of a child with leukemia/lymphoma: *“We're scraping by, we're getting by, so that's not so bad, but still a little stressful because if something comes up...[tearful pause] You know what I mean? Not like before, it was, something came up and (we’d) be like, ‘Oh, I got to tighten my belt until next week.’ But now it's more like, ‘well, there's no room for nothing.’ But that's how it is right now.”*
Theme 5: Financial coping behaviors	
• Driven by financial distress, material hardship, direct/indirect costs	Mother of a child with a solid tumor: *“So those were the things we had to think about was what do we do with insurance, employment. And so from the beginning I told him we can't both be here because we need to keep at least one insurance. And so we were just like, you have to work to keep that primary insurance. That's why he's working to keep it.”*

Table 4: Ameliorating and exacerbating factors across each theme, with illustrative quotes.

Theme	Ameliorating factors (with quote)	Exacerbating factors (with quote)
Direct costs	• More available family support • Shorter treatment duration • Shorter travel distance for care • Institutional housing (if relocated) • Medical insurance • Social work team involvement • Provision and use of resources *"For medical, nothing. Nothing. Everything's been completely free. That's the part I haven't worried about. Anything he needs medically the hospital's provided it and I haven't had to see a bill."*	• Less available family support • Longer treatment duration • Greater travel distance for care • Non-institutional housing (if relocated) • Worse patient health status *"You got to at least have $100 minimum to get to where we're going. And then the gas over there is cheaper, but you still need at least 100 bucks to get back. It takes a full tank basically. So it's 100 bucks each way for that, and then whatever on the way. My little one is like, 'I'm hungry, I'm this.' "*
Indirect costs	• Flexible or remote employment • Multiple employed caregivers • Shorter time traveling for care • Shorter treatment duration or intensity • Fewer caregiving requirements (patient as well as other family members) *"[My wife] was able to work remotely while over in Seattle both during the chemo process, as well as the radiation. Unfortunately, my job is more hands-on, so I wasn't able to do anything remotely or on a computer or anything. But they were pretty understanding of the situation and able to accommodate us."*	• Rigid, non-remote employment • Fewer available caregivers or support networks • Greater time traveling for care • Longer treatment duration or intensity • Larger caregiving requirements (patient as well as other family members) • Housing relocation *"Another thing that is noteworthy is childcare. So [father]'s still out of work, he is still home taking care of [patient] 100%. And that's largely also because in our community, there's no childcare for her that has the adequate abilities of changing a tube, or flushing a line, or putting the bag of food for her NG tube, administering medication."*
New material hardship	• Higher baseline income/wealth • Maintenance of employment during treatment • Support systems to provide resources, caregiving, and other support • Institution-provided resources • Shorter treatment duration *"Grandparents have definitely helped us a lot. They're the ones that have everything saved up from working all those years. So they've definitely helped if we needed anything, they provide it for us. And he's their only grandchild, at least [for] my parents. So it's like, anything for him."*	• Lower baseline income/wealth • Loss of employment • Fewer support systems • Greater direct costs • Existing bills that continued during treatment • Longer treatment duration *"There were times when I came to visit and I would open the fridge... Our fridge used to be full always, but at that time, I used to notice that it wasn't that full, it was kind of empty. …My husband never really said a thing as to not to worry me, but it was pretty evident… we weren't doing well. I mean, he tried to visit every two weeks, but there were times when he would call and say, 'You know what, I can't go,' for whatever reason. But I knew that he didn't have gas money to go, but I understood… because [we went] from having two sources of income to one."*
Psychological distress due to	• Familiarity with resources and early use • Connectivity with support systems • Fewer direct and indirect costs	• Unfamiliarity with resources or limited use • Isolation from support systems • Greater direct and indirect costs

financial changes	• Continuity with social work team *"We all just lean on each other. Even though, like I said, me and his dad aren't together, we try to work together. My fiancé, he's great. He's my rock. I can lean on him. I can tell him anything. He supports me, and he supports [patient]. It's just more of being able to have the people there and around you to understand what you're going through and have an open ear and a shoulder to cry on if you need it."*	• New material hardship • Uncertainty during treatment *"Okay, so honestly with a transplant coming up, we have some fear that's what's going to be our next big bill… it's going to be unknown how much it will be. So, it's mind boggling, instead of our mind just focusing on the transplant coming up, of course, you can't avoid thinking of your finances as well."*
Financial coping behaviors	• Less severe financial toxicity • Available and accessible support systems • Familiarity or experience with prior financial challenges • Support from social networks and community • Proactive and consistent support from social work and medical teams • Other resilience factors *"It's the government program where they take care of foster care… is like foster care, but it's run through a volunteer organization, churches, people who they're going to take care of your children. And then when you're ready, they'll give them back. It's not something you have to go through the court system for or anything like that. It's cool, yeah. And that was the biggest support that I immediately was like, 'I need some help.' "*	• More severe financial toxicity • Unavailable and inaccessible support systems • Lack of familiarity or experience with prior financial challenges • Isolation from social networks and community • Reactive or perceived inconsistent support from social work and medical teams *"We were thinking about selling our car because the car market is hot right now, people want to buy cars. But we were thinking about selling our vehicle because we have bills that we need to pay that are not medical expenses… And then going down to one income, we're trying to figure out how are we going to pay those bills off. We thought about selling our car but then that would leave us another barrier of not having good transportation."*

Supplemental Table: Demographic survey

DEMOGRAPHIC SURVEY (completed post-interview in REDCap)

1. How are you related to your child?
    - ☐ Mother
    - ☐ Father
    - ☐ Stepmother
    - ☐ Stepfather
    - ☐ Grandmother
    - ☐ Grandfather
    - ☐ Aunt or uncle
    - ☐ Older sibling
    - ☐ Other relative
    - ☐ Other

2. What is your gender?
    - ☐ Male
    - ☐ Female
    - ☐ I prefer to self-identify as: ________
    - ☐ I prefer not to answer

3. What is your current age (in years)?

4. What is the highest grade or level of school that you completed?
    - ☐ 8th grade or less
    - ☐ Some high school, but did not graduate
    - ☐ High school graduate or GED
    - ☐ Some college or 2-year degree (or trade or technical school)
    - ☐ 4-year college graduate
    - ☐ Graduate level degree (e.g., Master's) or higher
    - ☐ I prefer not to answer

5. What race or ethnicity do you identify with? Please choose one or more of the options below:
    - ☐ Black or African American
    - ☐ Latino or Hispanic
    - ☐ Asian
    - ☐ Native Hawaiian or Pacific Islander
    - ☐ American Indian, or Alaska Native
    - ☐ White or Caucasian
    - ☐ I prefer to self-identify as: _______________
    - ☐ I prefer not to answer

6. How many members, including you and your child, live in your household? _______

7. How many members in your household, including your child, are children? _______

8. How many members in your household, including you, are adult caregivers? _______

9. How many members in your household are adults who require full-time caregiving by another adult? __________

10. Which of the following best describes your housing at the time of your child's diagnosis:
    - ☐ House or townhouse – owned
    - ☐ House or townhouse – renting
    - ☐ Condo
    - ☐ Apartment
    - ☐ Temporary housing or shelter
    - ☐ No housing
    - ☐ I prefer not to answer

11. Do you have home internet access other than cell phone data?
    - ☐ Yes, broadband (high speed) internet AND unlimited access
    - ☐ Yes, non-broadband internet or limited broadband access
    - ☐ No home internet access

12. Does your home have reliable running water?
    - ☐ Yes
    - ☐ No
    - ☐ Don't know

13. Does your home have reliable plumbing/sewage?
    - ☐ Yes
    - ☐ No
    - ☐ Don't know

14. In the 12 months preceding your child's diagnosis, did your family have trouble affording electricity, heating, or other household utilities?
    - ☐ Often
    - ☐ Sometimes
    - ☐ Never
    - ☐ Don't know

15. In the 12 months preceding your child's diagnosis, have you worried about whether your food would run out before getting money to buy more, or being unable to afford enough food for your child(ren) to eat enough?
    - ☐ Often
    - ☐ Sometimes
    - ☐ Never
    - ☐ Don't know

16. In the 1 month preceding your child's diagnosis, did you ever need to limit the size or number of meals for your child(ren) because there was not enough money for food?
    - ☐ Often
    - ☐ Sometimes
    - ☐ Never
    - ☐ Don't know

17. What is the typical mode of transportation that your family uses for medical visits or emergencies?

- ☐ Private vehicle owned/leased by your household
- ☐ Private vehicle owned/leased by extended family or friends
- ☐ Public medical transport (HopeLink, etc.)
- ☐ Commercial ride share (Uber, Lyft) or taxi
- ☐ Bus
- ☐ Train
- ☐ Walking
- ☐ Other: _______
- ☐ I prefer not to answer

18. How many reliable vehicles does your household own or lease? ________

19. Does your household own or lease a reliable private vehicle that is available to transport your child to and from medical care in case of emergency?
    - ☐ Yes
    - ☐ No
    - ☐ Don't know

20. At the time of your child's diagnosis, approximately how long (in minutes) would it take to travel from your family's permanent residence to Seattle Children's Hospital? _______

21. How many caregivers were employed or working at the time of your child's diagnosis? _________

22. For caregivers who were working in your household, what were their occupation(s) at the time of your child's diagnosis? (Include more than one occupation if necessary): _________

23. Has there been a change in work/employment for any caregivers since your child's diagnosis?
    - ☐ Yes, directly related to my child's cancer diagnosis
    - ☐ Yes, unrelated to my child's cancer diagnosis
    - ☐ No, **Skip to Q26**
    - ☐ I prefer not to answer, **Skip to Q26**

24. What changes occurred in your family? Select all that apply.
    - ☐ A household member lost their job outside the home
    - ☐ A household member voluntarily left their job
    - ☐ A household member significantly reduced their working hours
    - ☐ Other (please specify): ______________
    - ☐ I prefer not to answer

25. Which family member(s) had the employment changes you described? (Include more than one family member if necessary):

26. Approximately what is your household's total gross annual income (before taxes)? ______

27. How stressed do you feel about your personal finances in general?
    - ☐ Not at all stressed
    - ☐ Rarely stressed
    - ☐ Somewhat stressed
    - ☐ Often stressed

- ☐ Always or almost always stressed
- ☐ I prefer not to answer

28. Was there any change in the childcare situation of your child receiving treatment? Please select all that apply.
    - ☐ Yes, child is no longer in daycare/school outside the home
    - ☐ Yes, we employed an in-home caregiver (e.g., nanny)
    - ☐ Yes, a family member or friend now provides in-home childcare
    - ☐ No, no change in my child's childcare
    - ☐ Other (please specify): ______________
    - ☐ I prefer not to answer

29. Are there other children in the home?
    - ☐ Yes
    - ☐ No, **Finish survey**
    - ☐ I prefer not to answer, **Finish survey**

30. Was there any change in the childcare situation for the other child(ren) in the home? Please select all that apply.
    - ☐ Yes, child(ren) is/are no longer in daycare/school outside the home
    - ☐ Yes, we employed an in-home caregiver (e.g., nanny)
    - ☐ Yes, a family member or friend now provides in-home childcare
    - ☐ No, no change in childcare
    - ☐ Other (please specify): ______________
    - ☐ I prefer not to answer