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Household material hardship in families of children post-chemotherapy

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Abstract

Poverty is an important patient-reported outcome of therapy and a potential predictor of outcome disparities in pediatric cancer. We previously identified that nearly 30% of pediatric cancer families experience household material hardship (HMH), a concrete measure of poverty including food, energy, or housing insecurity, during the first 6 months of chemotherapy. We conducted a follow-up survey in a subcohort of these families at least 1 year off-therapy and found that 32% reported HMH in early survivorship. Persistently high concrete resource needs off-therapy may have significance for child health and quality of life, and thus represent targets for future investigation.

Keywords

outcomes; pediatric oncology; postchemotherapy; poverty; quality of life; survivorship

1 | INTRODUCTION

Recent literature has identified social determinants of health—nonbiological correlates of health outcomes such as poverty, financial burden, or medication adherence—as targets for investigation in the early childhood cancer treatment setting.^{1–5} In 2016, the strong correlation between poverty and inferior pediatric health outcomes prompted the American Academy of Pediatrics to recommend universal pediatric poverty screening.⁶ Concurrently, the Children's Oncology Group and American Psychosocial Oncology Society endorsed new standards acknowledging financial strain as an important patient-reported outcome and “strongly recommended” systematic screening from diagnosis into survivorship or bereavement.^{7,8}

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

Household material hardship (HMH), including food, housing, or energy insecurity, is an appealing concrete measure of financial burden as it is associated with health outcomes in general pediatrics⁹ and can be ameliorated through systematic linkage with government or community resources.^{10,11} We previously described the frequency of HMH in a cohort of newly diagnosed pediatric cancer families and found that, in concert with national data, 20% were experiencing HMH at diagnosis.^{1,12,13} This increased to nearly 30% following 6 months of chemotherapy.¹ We now sought to describe the frequency of HMH and financial burden in early survivorship and hypothesized that both patient-reported outcomes would be prevalent.

2 | METHODS

We utilized a subcohort of the previously published Oncology Economic Impact Study (Onc EIS) to conduct a cross-sectional “Long-Term Follow-up” (T3) survey of HMH at least 1 year off-therapy from October 31, 2014 through September 15, 2015.¹ Onc EIS was a prospective two time-point survey investigation of HMH in 99 newly diagnosed pediatric cancer families treated at Dana-Farber/Boston Children’s Cancer and Blood Disorders Center in Boston, Massachusetts from 2011 to 2013.¹ Onc EIS participants completed a baseline survey within 30 days of diagnosis and a follow-up survey after 6 months of chemotherapy.

Participants in this follow-up study completed the additional T3 survey at least 1 year off-therapy. This study was approved by the Dana-Farber Cancer Institute Institutional Review Board.

2.1 | Study population

Eligibility criteria for T3 included (1) Onc EIS participant who completed baseline and 6 month surveys and agreed to future contact, (2) child at least 1 year off-therapy, (3) child neither relapsed nor died, and (4) primary team permission to approach.

2.2 | Data collection

Of the N = 99 Onc EIS cohort, 68 (69%) families were eligible for T3. Eligible families were contacted by a research assistant and asked to complete a one-time survey either in-person or via telephone; questions were read aloud. The 77-item T3 survey included domains of (1) demographics, (2) HMH, (3) employment and income, and (4) financial impact.

2.3 | Operational definition of variables

In concert with prior publications, we defined a family as having HMH if they endorsed at least one unmet need including food, energy, or housing.^{1,9} Year-specific federal poverty levels (FPLs) were based on the Department of Health and Human Services Poverty Guidelines and calculated as follows: baseline family income was divided by the year-specific poverty guideline for household size and multiplied by 100 to achieve percentage of FPL.¹⁴

2.4 | Statistical methods

We summarized child, family, and financial characteristics using descriptive statistics including frequencies, proportions, medians, interquartile ranges (IQRs), and ranges. To compare baseline characteristics between T3 participants and those either ineligible for T3 or who declined actively or passively to participate, we used Fisher's exact test and Wilcoxon rank sum test to test categorical and continuous variables, respectively. Two-sided P values <0.05 were considered significant. Analyses were conducted using SAS v. 9.4 for Windows (SAS Institute, Cary, NC).

3 | RESULTS

Of the 68 families eligible for T3, 15 were unreachable, 53 were successfully contacted, and 52 consented to participate (76% response rate). The T3 survey was administered at least 1 year from the completion of therapy, a median of 2.6 years (1.3–3.7) from diagnosis; 42 (81%) surveys were administered by phone and 10 (19%) in-person.

To assess potential biases between T3 participants ($N = 52$) and nonparticipants (including those ineligible to participate or who declined to participate) ($N = 47$), we compared baseline characteristics between the two groups. While demographics at time of diagnosis did not differ statistically between T3 participants and nonparticipants, we noted a trend toward higher socioeconomic status in T3 families. At diagnosis, fewer T3 families reported HMH (15% vs. 26%; Fisher's exact test $P = 0.22$) and more T3 families reported at least a college degree (83% vs. 68%; $P = 0.1$). Child disease characteristics did not differ statistically between groups, nor were there notable trends.

4 | T3 PARENT AND HOUSEHOLD CHARACTERISTICS AT BASELINE

A majority of parents were white (81%) and college educated (83%) (Table 1). Nearly all (96%) were employed with a median household income of \$101,012 (IQR \$72,690–\$182,500), above the \$83,700 median household income for families in Massachusetts.¹⁵

5 | HOUSEHOLD MATERIAL HARDSHIP

At diagnosis, 15% of families reported HMH. This increased to 33% after 6 months of chemotherapy, and persisted at 33% at T3 (Fig. 1). Family-reported food and energy insecurity, for which comparative national data exist, were significantly lower at baseline (8% each) than national averages (20% and 18%, respectively).^{12,13}

6 | IMPACT OF CHILD'S TREATMENT ON FAMILY FINANCES

Thirty-six percent of families ($N = 18/50$) reported losing $>40\%$ annual household income due to treatment-related work disruptions; median percent income lost was 22% (IQR 4.3–50). Forty-four percent of families endorsed experiencing “a great deal of financial hardship” due to their child's illness and reported that they were “just getting by living paycheck to paycheck” all or most of the time. As a result of their child's cancer and treatment, 40% (17/43) of families with a retirement fund at baseline stopped or reduced

payments, and 50% (10/20) of families with a college fund at baseline stopped or reduced payments.

7 | DISCUSSION

We previously reported that 29% of pediatric oncology families at a large referral center experienced food, housing, or energy insecurity following 6 months of chemotherapy.¹ We now describe HMH in the early off-therapy period. Strikingly, in this socioeconomically advantaged subcohort of our original investigation, the percentage of families reporting HMH doubled (15–33%) from baseline to off-therapy. Considering these data reflect the experience of a predominantly white, college-educated cohort with baseline incomes above the median at diagnosis, our findings highlight both the significant financial strain of pediatric cancer therapy and the vulnerability of “middle class” families unlikely to raise red-flags for resource needs at diagnosis. They further beg the question of what financial hardship lower income families are experiencing in early survivorship.

Our data represent a single center and a relatively small, socioeconomically advantaged cohort. This clear limitation may bias our findings toward underestimating the prevalence of HMH in a more socioeconomically diverse pediatric cohort. While administered *at least* 1 year off-therapy, the T3 survey was not given at a standardized time-point that limits our ability to describe time-specific outcomes. These data provide a first descriptive highlight of a seemingly significant problem in pediatric oncology.

Poverty—including HMH—is associated with inferior general pediatric health outcomes including metabolic syndrome, cardiovascular effects, delayed development, chronic illness, and injury.^{6,7,9,16–19} It is plausible that household poverty in the off-therapy setting may have implications for child health in survivorship—including adherence to recommended screening or risk of late effects. Over one in three children from middle class families appear to be living in homes with unmet basic resource needs during early cancer survivorship. Further investigation of the prevalence and impact of such need is warranted.

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Abbreviations

FPL	federal poverty level
HMH	household material hardship

IQR interquartile range

Onc EIS Oncology Economic Impact Study

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FIGURE 1. Material hardship within 30 days of diagnosis, after 6 months of chemotherapy, and at least 1 year off therapy (N = 52). *Error bars represent frequency $\pm$ 1 standard error

TABLE 1

Baseline child and family characteristics of long-term follow-up survey (T3) respondents (N = 52)

Frequency (%) or Median (p25, p75)	
Parental demographics at baseline	
Parent completing survey: mother	32 (62)
Parent age	39.3 (33.7, 46.2)
Education	
High school education or less	9 (17)
Associate/bachelors	24 (46)
Masters/doctorate	19 (37)
Ethnicity: Hispanic or Latino	2 (4)
Race: non-White	10 (19)
Household characteristics at baseline	
English as primary language	50 (96)
Single parent household	7 (14)
Household size	4 (4, 5)
Distance of home from DFCI (miles)	
0–50	40 (77)
50+	12 (23)
Household income at diagnosis (dollars)	101,012 (72,690, 182,500)
Any parent in household unemployed at diagnosis (excluding stay at home parents)	2 (4)
Child, disease, and care characteristics	
Female	32 (62)
Age at diagnosis	5.5 (3, 12)
Cancer diagnosis	
Hematologic malignancy	28 (54)
Solid tumor	15 (29)
Brain tumor	9 (17)
Health insurance	
Private ± Masshealth/Medicaid	43 (83)
Medicaid/MassHealth only	9 (17)
Uninsured	0 (0)

p25, p75: 25th percentile, 75th percentile.