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What we did not learn from an exploratory analysis of economic hardship in newly diagnosed adolescents and young adults with cancer

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To the editor: Recently established psychosocial standard of care guidelines highlight the importance of financial burden risk assessment at cancer diagnosis.¹ These are founded upon literature suggesting pediatric cancer families are at high risk of economic hardship, parental work disruptions, and income loss, which is further associated with poor family wellbeing and distress.¹⁻³

"Perceived" economic hardship may be conceptually distinct from income-based hardship and has been found to negatively influence parent distress even after adjusting for household income.^{2,4} Few studies have assessed relationships between household income, perceived economic hardship, and distress early after cancer diagnosis. Thus, we conducted a post-hoc exploratory analysis of the "Resilience in Adolescents and Young Adults (AYAs) with Cancer" Study^{5,6} to evaluate these relationships among 23 English-speaking AYAs with cancer (ages 14–25) and 26 parents. Data were collected at initial cancer diagnosis (Time 1: T1), and 3–6 months later (T2). T1 assessed household income, and AYA and parent psychological distress (Kessler-6 Scale⁷). T2 assessed these same variables plus income loss, work disruptions, and perceived treatment-related economic hardship. Perceived economic hardship was assessed via the question, "How much of a financial hardship has this illness been for your family?" on a four-point Likert scale ranging from "1 = great economic hardship" to "4 = no economic hardship". All but one of the AYAs were still living at home with their parents, and we do not know whether financial burden was explicitly discussed between AYAs and other family members.

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Conflict of Interest

The Authors have no conflicts of interest to report.

69% of parents at T1 and 65% at T2 reported annual household incomes of \$100,000. Only 12% of families qualified as low-income (i.e., <200% Federal Poverty Level). Compared to an expected 20% rate of household material hardship in newly diagnosed pediatric oncology families^{1,8}, housing, food, and electricity insecurity were reported by 4%, 8%, and 12% of families, respectively, with a 23% total rate of material hardship in any domain.

Despite the objective high socioeconomic status of our cohort, 39% of AYAs and 42% of parents reported moderate to great levels of perceived economic hardship at T2. Similar to previous pediatric oncology studies¹, about half of parents reported work disruptions, and 62% reported treatment-related income loss at T2 (Mean Income Loss = 12% annual household income).

In our small cohort, neither perceived economic hardship nor baseline household income was related to psychological distress at T1 or T2 for AYAs or parents in our sample using simple correlations; $r=-0.19$ to 0.16 , $p=0.37$ to 0.91 , and $r=-.071$ to $-.25$, $p=.24$ to $.73$, respectively.

This exploratory investigation suggests that among an economically advantaged cohort of families, a strikingly high percentage identify perceived cancer-related economic hardship early in treatment. Prior work by our group identified an association between perceived hardship and parent distress in the advanced cancer setting.² While perceived economic hardship was unrelated to objective measures of material hardship or baseline income, it is unclear whether this was due to a lack of statistical power versus absence of relationship in the early treatment setting.

Our study targeted a gap in the literature which has focused on objective (not subjective) measures of treatment-related economic hardship. However, our data do not elucidate when during treatment distress and perceived economic hardship intersect. Additional prospective research is needed to determine the timing and cumulative impact of perceived economic hardship on patient and family wellbeing and psychological outcomes.

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Abbreviation

AYAs	Adolescents and Young Adults
T1	Time 1

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