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Prevalence and Impact of Financial Hardship among New England Pediatric Stem Cell Transplantation Families

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A B S T R A C T

Poverty is correlated with negative health outcomes in pediatric primary care and subspecialties; its association with childhood hematopoietic stem cell transplantation (HSCT) patterns of care and clinical outcomes is not known. We describe family-reported financial hardship at a primary referral center in New England and explore the relationship between measures of poverty and patterns of care and clinical outcomes. Forty-five English-speaking parents of children after allogeneic HSCT in the prior 12 months completed a 1-time survey (response rate 88%). Low-income families, defined as ≤200% federal poverty level (FPL), were compared with all others. Eighteen (40%) families reported pre-HSCT incomes ≤200% FPL. Material hardship, including food, housing, or energy insecurity was reported by 17 (38%) families in the cohort. Low-income families reported disproportionate transplantation-related income losses, with 7 (39%) reporting annual income losses of >40% compared with 2 (18%) wealthier families ($P = .02$). In univariate analyses, 11 (61%) low-income children experienced graft-versus-host disease (GVHD) of any grade in the first 180 days after HSCT compared with 2 (7%) wealthier children ($P = .004$). We conclude that low income and, in particular, material hardship, are prevalent in a New England pediatric HSCT population and represent targets for improvement in quality of life. The role of poverty in mediating GVHD deserves further investigation in larger studies that can control for known risk factors and may provide a targetable source of transplantation-associated morbidity.

INTRODUCTION

Pediatric allogeneic hematopoietic stem cell transplantation (HSCT) can provide life-saving treatment for children with malignant and nonmalignant diseases. Steady advances in HSCT donor selection, stem cell source, conditioning regimens, and supportive care have led to improved medical outcomes, and the frequency of HSCT in pediatrics is increasing annually [1]. Despite these advancements, pediatric HSCT remains a physically and emotionally demanding treatment for children and their families. Transplantation-related morbidity and mortality remain substantial [1], and research into the psychosocial impact of pediatric HSCT has demonstrated high levels of family distress despite standard institutional supportive care interventions [2,3].

Financial hardship is increasingly being recognized as a consequence of adult and childhood cancer treatment [4-12]. Poverty is known to be correlated with negative health outcomes, including mortality, in pediatric primary care and chronic illness [13-25]. Studies in families of children with cancer report that financial distress is associated with frequent admissions, consequent work disruptions, and limited access to financial support [12,26]. High-risk pediatric cancer families include those whose children experience long admissions, those treated far from home, and poorer families [5,9,27]. Data about parental employment in pediatric cancer suggest that as many as three quarters of parents suffer work disruption because of therapy [5,8,9]. Resultant catastrophic financial hardship, including income losses of >40% due to treatment, has been described in up to 20% of families of children with advanced cancer and bereaved families [8,9]. Moreover, families with low income before therapy disproportionately suffer such impact [8,9]. Despite this emerging evidence of substantial financial

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distress in families of children with cancer, little is known about the economic hardship experienced by families of children undergoing pediatric HSCT.

It stands to reason that the more intensive treatment characteristics of HSCT—including prolonged inpatient admissions, therapy far from home at referral centers, and the need for full-time parental caretaking secondary to isolation precautions—may impose an even greater burden on families than chemotherapy alone. Indeed, recent studies in adult recipients of allogeneic HSCT have demonstrated substantial financial burden [28,29]. For example, in a retrospective survey of adult HSCT survivors, Khera et al. found that more than two thirds reported their sickness had hurt them financially, and nearly one half reported transplantation-related household income losses of >50% [28].

Though disease relapse represents the leading cause of post-transplantation death in pediatric HSCT, transplantation-related complications including graft-versus-host disease (GVHD) and infection continue to account for significant morbidity and mortality [1]. Identification of children at increased risk for these complications based on donor and recipient biologic characteristics has allowed for more individualized preventive measures [30]. Although little is known about the role of socioeconomic status in mediating HSCT complications in children, recent studies in adults have provided provocative evidence that socioeconomic status may affect these outcomes [31,32]. To our knowledge, no studies have explored the prevalence of poverty and financial burden in pediatric HSCT, nor have any examined the relationship between measures of poverty and HSCT outcomes in children. We aimed to describe the prevalence of family-reported income poverty and concrete resource needs—2 important measures of financial hardship—in families of children undergoing allogeneic HSCT at a major pediatric referral center in New England. We further sought to describe the impact of HSCT on parental employment and income and to explore the relationship between baseline family income poverty and child patterns of care and clinical outcomes.

MATERIALS AND METHODS

The Stem Cell Transplant Economic Impact Study (SCT EIS) was conducted at Dana-Farber/Boston Children's Cancer and Blood Disorders Center (DF/BCH) in Boston, Massachusetts. DF/BCH is the primary regional referral center in New England for pediatric stem cell transplantations serving children from Massachusetts, Maine, New Hampshire, Vermont, Rhode Island, and Connecticut as well as national and international referrals. This study was approved by the Dana-Farber Cancer Institute's institutional review board.

Study Population

The SCT EIS was administered in a cross-sectional cohort of pediatric transplantation families whose child had undergone allogeneic stem cell transplantation for any underlying disease at DF/BCH between December 2010 and September 2012. Parents/legal guardians were eligible to participate if the child's transplantation occurred a minimum of 30 days and a maximum of 12 months before survey completion, the parent/legal guardian spoke English, and the primary treating physician provided permission to approach. Parents of children who had died during or after transplantation and before our ability to approach for consent were excluded from participation. Foreign national families residing in Boston exclusively for the child's transplantation with intent to return to their native country shortly after transplantation were also excluded from participation.

Clinical Care Team Context

All children enrolled in this study received psychosocial support services per institutional standard. Consequently, 100% of families enrolled in this study had a dedicated psychosocial clinician who followed them from the time of transplantation through the post-transplantation time period to address the emotional consequences of illness. In addition, 100% of families met with a member of the pediatric hematology/oncology resource specialist team, which focuses exclusively on identifying and ameliorating concrete resource needs for families undergoing pediatric cancer treatment or stem cell transplantation, at the time of transplantation.

Data Collection

Survey administration

We identified 65 eligible families and the primary provider permitted approach in 63 of these. Fifty-one of the 63 eligible families were approached in person by the study's principal investigator (PI) or a trained research assistant in the outpatient clinic or inpatient floor; 12 families attended clinic visits on days neither the PI nor research assistant were available to consent and, thus, were not approached. Participants completed a 1-time, face-to-face survey at the time of enrollment. Survey questions were read aloud to participating parents; thus, the ability to read or write was not necessary. Joint parental participation in answering questions about family finances was allowed. One parent was asked to identify himself or herself as the primary study participant to answer demographic and psychosocial questions. Employment and income questions were asked about all adults financially supporting the child. Surveys were administered between August 2011 and April 2013, a median of 132 (interquartile range [IQR], 96) days after transplantation, and administration took an average of 39 minutes.

Instrument development

The 120-item SCT EIS survey was developed with the aim of exploring 4 domains of family economics: (1) baseline prevalence of income poverty, (2) impact of the child's transplantation on parental employment, family income, and reported financial security, (3) prevalence of material hardship during the post-transplantation period, and (4) the relationship between family income and child's outcomes. Where possible, the survey incorporated questions from previously published instruments [33-37]. Additional survey items were derived de novo based on a comprehensive review of the general pediatric and subspecialty pediatrics literature; interviews with HSCT and pediatric oncology families; and consensus opinions from pediatric stem cell transplantation physicians, pediatric oncologists, palliative care physicians, and resource specialists. All items were closed-ended questions or multiple choice. The survey was piloted in face-to-face interviews with pediatric oncology and HSCT families to refine the domains of inquiry and assess item wording, respondent burden and willingness to participate. The survey instrument is available in the Appendix S1.

Chart abstraction

Medical chart abstraction was performed by a trained research assistant and duplicated by the PI for each patient from the date of stem cell infusion through 6 months after transplantation. Discrepancies between the 2 abstracters were discussed, and final coding was determined by consensus. Data elements included date of birth, gender, HSCT medical indication, HSCT source, HSCT conditioning regimen, duration of hospitalization for HSCT, number of unplanned admissions after HSCT, any intensive care unit stay, and occurrence of any GVHD.

Operational Definition of Variables

Material hardship

Material hardship was assessed in 3 domains: food insecurity, housing insecurity, and energy insecurity. Housing insecurity and energy insecurity are constructs for which no official United States measures exist. We chose to assess these concrete resource needs in accordance with previously published general pediatrics measures known to have statistically significant associations with child health outcomes [15,16].

Food insecurity. Measured and defined utilizing the validated US Household Food Security Survey Module: Six-Item Short Form and scored in accordance with established guidelines [34,38]. This measure utilizes a standardized 12-month reference period, which, therefore, was not specific to but included the post-transplantation period.

Housing insecurity. Families were considered to be "housing insecure" if they reported any of the following: (1) crowding, defined as >2 people per bedroom in the home at the time of survey administration after transplantation, (2) multiple moves, defined as >1 move in the prior year in response to the question, "How many places have you and your child lived in the past year," or (3) doubling up after transplantation, defined as an affirmative answer to the question, "Since your child's transplantation, have you and your child had to temporarily live with other people, even for a little while, because of financial difficulties?"

Energy security. Families were considered to be "energy insecure" if they answered affirmatively to any of the following questions: (1) "Since your