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Financial Hardship and Patient-Reported Outcomes after Hematopoietic Cell Transplantation

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A B S T R A C T

Although hematopoietic cell transplantation (HCT) is the only curative therapy for many advanced hematologic cancers, little is known about the financial hardship experienced by HCT patients nor the association of hardship with patient-reported outcomes. We mailed a 43-item survey to adult patients approximately 180 days after their first autologous or allogeneic HCT at 3 high-volume centers. We assessed decreases in household income; difficulty with HCT-related costs, such as need to relocate or travel; and 2 types of hardship: hardship_1 (reporting 1 or 2 of the following: dissatisfaction with present finances, difficulty meeting monthly bill payments, or not having enough money at the end of the month) and "hardship_2" (reporting all 3). Patient-reported stress was measured with the Perceived Stress Scale-4, and 7-point scales were provided for perceptions of overall quality of life (QOL) and health. In total, 325 of 499 surveys (65.1%) were received. The median days since HCT was 173; 47% underwent an allogeneic HCT, 60% were male, 51% were > 60 years old, and 92% were white. Overall, 46% reported income decline after HCT, 56% reported hardship_1, and 15% reported hardship_2. In multivariable models controlling for income, those reporting difficulty paying for HCT-related costs were more likely to report financial hardship (odds ratio, 6.9; 95% confidence interval, 3.8 to 12.3). Hardship_1 was associated with QOL below the median (odds ratio, 2.9; 95% confidence interval, 1.7 to 4.9), health status below the median (odds ratio, 2.2; 95% confidence interval, 1.3 to 3.6), and stress above the median (odds ratio, 2.1; 95% confidence interval, 1.3 to 3.5). In this sizable cohort of HCT patients, financial hardship was prevalent and associated with worse QOL and higher levels of perceived stress. Interventions to address patient financial hardship—especially those that ameliorate HCT-specific costs—are likely to improve patient-reported outcomes.

INTRODUCTION

Hematopoietic cell transplantation (HCT) is the only curative therapy for many advanced blood cancers. Although it is a resource-intensive procedure associated with high costs to the medical system [1-8], little is known about how financial hardship manifests for patients and their families. Familial financial hardship may arise from income decrement after HCT, insurance deductibles or coinsurance, and/or from additional HCT-specific costs. For example, many patients must temporarily relocate near a HCT center or otherwise have difficulty with transportation for frequent clinic appointments. Moreover, the post-HCT recovery period can be lengthy and often leads to extended time away from work [9,10]. Wage replacement for patients is not universally available, as 45% of all workers in the United States are without any paid sick days [11]. Caregivers can also experience financial hardship because of travel expenses, time away from work, and accommodations for patient treatment [12-14].

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Several retrospective studies have suggested that patients experience significant changes in quality of life (QOL) after HCT [15-20], that financial concerns are likely prevalent among these patients before and after the procedure [21,22], and that these concerns may affect patient-reported outcomes (PROs) [9,10,22]. Financial hardship after HCT may also contribute to poor post-HCT treatment adherence [23] and may even compromise HCT outcomes such as survival [24]. Given the extensive support typically available to HCT patients (physicians, nurses, social workers, and financial resource specialists), if financial hardship is shown to be prevalent and affect PROs, such data would not only be important for HCT patients but it would also be instructive for those taking care of patients with other resource-intensive malignancies with less support.

Lower socioeconomic status has been associated with poor survival for blood cancers [25,26] and also specifically with worse post-HCT survival [27]. Although pre-HCT measures of socioeconomic status such as household income are undoubtedly related to post-HCT financial hardship, we posit that they are not the same. Indeed, even when household income is controlled, measures of financial hardship may remain significantly associated with health outcomes [28,29]. Some patients with lower income levels might be partially protected from financial hardship because of pre-existing supports, such as access to government benefits, whereas others with relatively higher pre-HCT incomes may have more extensive financial commitments and, thus, may be highly susceptible to new post-HCT costs and income changes.

Through a mailed survey design, we aimed to characterize financial hardship after HCT and its association with outcomes such as perceived stress, QOL, and overall health by specifically asking patients and their families about their finances while they were going though the post-HCT period. We hypothesized that familial hardship would be prevalent among patients after HCT and more intense among those who reported HCT-specific factors, such as high transportation costs. We also hypothesized that those with higher levels of financial hardship would report worse QOL and overall health and higher levels of perceived stress.

METHODS

Study Design and Participants

We undertook a cross-sectional observational study to characterize the financial experience of patients at 6 months after HCT and its association

Table 1
Characteristics of Survey Respondents

Respondent Characteristic	All Sites n = 325 (%)	DFCI n = 228 (%)	MCA n = 59 (%)	RPCI n = 38 (%)
HCT type				
Autologous	172 (53%)	112 (49%)	38 (64%)	22 (58%)
Allogeneic	153 (47%)	116 (51%)	21 (36%)	16 (42%)
Diagnosis				
Multiple myeloma	104 (32%)	67 (29%)	25 (42%)	12 (32%)
Non-Hodgkin lymphoma	79 (24%)	64 (27%)	5 (8%)	10 (26%)
Acute myeloid leukemia	57 (17%)	41 (17%)	8 (13%)	8 (21%)
Myelodysplastic syndromes	30 (9%)	24 (10%)	2 (3%)	4 (11%)
Hodgkin lymphoma	20 (6%)	15 (6%)	5 (8%)	0 (0)
Acute lymphoblastic leukemia	13 (4%)	11 (5%)	2 (3%)	0 (0)
Other	32 (10%)	15 (6%)	13 (22%)	4 (11%)
Sex				
Female	130 (40%)	94 (41%)	22 (37%)	14 (37%)
Male	195 (60%)	134 (59)	37 (63%)	24 (63%)
Age, yr				
≤60	160 (49%)	115 (50%)	32 (54%)	13 (34%)
>60	165 (51%)	113 (50%)	27 (46%)	25 (66%)
Race				
White	294 (92%)	215 (96%)	45 (78%)	34 (90%)
Non-white	27 (8%)	10 (4%)	13 (22%)	4 (11%)
Insurance type				
Employer sponsored	198 (62%)	144 (64%)	33 (56%)	21 (55%)
Government sponsored	99 (30%)	65 (29%)	23 (39%)	11 (29%)
Self-insured	25 (8%)	16 (7%)	3 (5%)	6 (16%)
Employment status				
Employed	142 (44%)	107 (49%)	23 (39%)	12 (32%)
Unemployed	13 (4%)	10 (4%)	4 (2%)	2 (5%)
Not in the labor force	169 (52%)	110 (48%)	35 (59%)	24 (63%)
Marital status				
Married	89 (73%)	135 (73%)	43 (74%)	26 (68%)
Not married	234 (28%)	62 (27%)	15 (26%)	12 (32%)
Education				
BA/graduate degree	155 (48%)	112 (49%)	30 (51%)	13 (34%)
No BA/graduate degree	169 (52%)	115 (51%)	29 (49%)	25 (66%)
Monthly income				
Low income (<$3000)	92 (29%)	61 (28%)	17 (30%)	14 (37%)
Middle income ($3000 to $6999)	139 (44%)	100 (45%)	25 (45%)	14 (37%)
High income (>$7000)	84 (27%)	60 (27%)	14 (25%)	10 (26%)
Distance				
≥112 miles (75th percentile)	242 (75%)	164 (72%)	48 (84%)	30 (79%)
<112 miles	81 (25%)	64 (28%)	9 (16%)	8 (21%)

DFCI indicates Dana-Farber Cancer Institute; MCA, Mayo Clinic Arizona; RPCI, Roswell Park Cancer Institute; BA, Bachelor of Arts or Science.
Data presented are n (%), unless otherwise indicated. Categories may not add up to 100% due to rounding. No categories were significantly different by HCT study sites except for time since day 0, diagnosis, and race.