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Pilot Study of Patient and Caregiver Out-of-Pocket Costs of Allogeneic Hematopoietic Cell Transplantation

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Abstract

Patient/caregiver out-of pocket costs associated with hematopoietic-cell transplantation (HCT) are not well known. We conducted a pilot study to evaluate patient/caregiver out-of-pocket costs in the first 3 months after allogeneic HCT. Thirty patients were enrolled at three sites. Prior to HCT, participants completed a baseline survey regarding household income and insurance coverage. Subsequently, they maintained a paper-based diary to track daily out-of-pocket expenses for the first 3 months after HCT. Telephone interviews were conducted to followup on missing/incomplete diaries and on study completion. Twenty-five patients/caregivers completed the baseline survey. Among these, the median pre-tax household income was $66,500 (range, $30-$375,000) and 48% had to temporarily relocate close to the transplant center. Insurance coverage was managed care plan (56%), Medicaid (20%), Medicare (17%) and other (8%). Twenty-two patients/caregivers completed ≥4 diaries; the median out-of-pocket expenses were $2,440 (range, $199-$13,769). Patients/caregivers who required temporary lodging had higher out-of-pocket expenses compared to those who did not (median, $5,247 vs. $716). Patients/caregivers can incur substantial out-of-pocket costs over the first 3 months, especially if they need to temporarily relocate close to the transplant center. Our study lays the foundation for future research on early and long-term financial impact of allogeneic HCT on patients/caregivers.

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SUPPLEMENTAL INFORMATION Supplementary information related to this study is available at BMT's website.

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Keywords

Allogeneic hematopoietic-cell transplantation; financial impact; costs; out-of-pocket expenses

INTRODUCTION

Allogeneic hematopoietic cell transplantation (HCT) is an expensive medical procedure. Hospital and transplant center related costs of allogeneic HCT are described in the literature.[1-8] Patients undergoing allogeneic HCT and their caregivers can have significant financial challenges throughout the transplant process that are generally not reflected in estimates of hospital and transplant center costs. In treating their underlying disease, many patients incur out-of-pocket medical expenses and loss of income even prior to transplantation. The HCT procedure is only available at select centers and patients may need to relocate to temporary housing for medical care. HCT is also marked by a lengthy recovery period and high potential for medical complications that may lead to extended time away from work for patients and caregivers. This sometimes leads to further financial hardship as patients/caregivers may lose work related benefits (e.g. paid leave, employer contribution to health insurance premiums). Medical costs such as clinic and prescription co-payments frequently continue through the recovery period.

Out-of-pocket expenses can impact care and adherence among cancer patients. Patients who are financially strained are more likely to forego recommended care, treatment and followup. Even among insured patients, the cost of cancer diagnosis and treatment can present a major barrier to obtaining high quality care.[9-11] Patient and caregiver out-of-pocket costs following HCT are not well described.[12-14] In a study of 40 autologous HCT recipients, median out-of-pocket expenses during the inpatient period were $849.35 for caregivers who stayed in local accommodations and $181.15 for caregivers who stayed in the patient's hospital room.[12] In another study of 21 autologous HCT recipients, the median out-of-pocket and indirect costs for caregivers were $382 and $2,520, respectively, for a median patient hospital stay of 15 days.[13] Rizzo et al, in the context of a larger study comparing costs of inpatient and outpatient HCT (autologous and allogeneic), surveyed 53 one year survivors about out-of-pocket costs and observed no difference between patients receiving inpatient and outpatient transplantation.[14]

Several factors may determine the amount and type of patient and caregiver out-of-pocket costs of HCT. Distance from the transplant center, the need to relocate closer to the center and availability of support and resources both at home and locally around the center are likely to be important determinants of out-of-pocket costs. Other factors may include type of transplant and insurance coverage. Recipients of autologous HCT are frequently discharged from transplant centers sooner than allogeneic HCT recipients and may not incur the same patient expenses. Patient health insurance may also impact out-of-pocket costs based on coverage for travel and relocation and co-pays/deductibles for hospitalizations, clinic visits and prescriptions. Overall, there is a need to better understand the financial impact of HCT on patients and their families. In this report, we describe the results of our pilot study that

evaluated patient and caregiver out-of-pocket costs in the first 3 months after allogeneic transplantation.

PATIENTS AND METHODS

Patient Eligibility

Three centers participated and enrolled 10 patients each: University of Minnesota, Medical College of Wisconsin and Roswell Park Cancer Institute. Adult recipients and parents/guardians of pediatric recipients of related and unrelated donor HCT were eligible to participate. Since our main interest was studying household finances around the time of transplantation, we restricted participation to patients whose underlying disease had been diagnosed within 2 years of transplantation. There were no restrictions on diagnosis, donor source, graft source or conditioning regimen. Participants were required to have a caregiver who was a member of the patient's household. Patients and their caregivers had to be proficient in English. Patients who had previously received a transplant and patients from households with another HCT recipient were excluded from participation in this study. The study was conducted under the guidance of the Institutional Review Boards of the National Marrow Donor Program® (NMDP) and the three participating sites. Both the patient and caregiver provided informed consent. Caregivers were allowed to continue on the study in the event of patient death. Patients also provided consent to participate in the Center for International Blood and Marrow Transplant Research (CIBMTR) research database for collection of clinical data.

Pilot Study Design

Study coordinators at each site consented patients/caregivers and sent their information to the study coordinator at the CIBMTR. Upon registration, patients/caregivers received a packet containing a baseline survey of household financial information, out-of-pocket income/expense diaries and instructions for completing both. Patients/caregivers could call a toll-free phone number if they had questions regarding the study instruments. Pre-paid postage envelopes were provided for returning completed study materials to the CIBMTR. All materials were organized in a pocket folder that also had space for any documents and receipts to assist with organizing financial data.

Patients/caregivers were asked to maintain a bi-weekly diary to track out-of-pocket expenses and were instructed to begin completing the first diary on the day of transplant admission. Patients/caregivers completed a total of 6 diaries which covered the first 3 months post-transplantation. Study coordinators from the CIBMTR contacted patients/caregivers by phone, as needed, to followup on diaries that had not been submitted and to clarify diary entries. Upon study completion, study coordinators conducted a structured phone interview with study participants to assess their satisfaction with study procedures and solicit suggestions for improving the diary.

Study participants received a $35 gift card upon submission of the baseline survey, on receipt of each completed out-of-pocket income/expense diary, and following completion of

the study evaluation. Funds for gift cards were provided by the NMDP. Data on disease and transplant characteristics were obtained from the CIBMTR database.

Study Instruments

The baseline survey contained 65 items and was designed to capture detailed information on patient and caregiver household finances. We also asked about health insurance information, the impact of previous therapy on household finances and patient/caregiver confidence in meeting their household's financial obligations during the transplant process.

We developed a diary to capture patient/caregiver out-of-pocket expenses. We used two resources to inform the design of this instrument. First, we conducted a literature review and identified previously reported instruments for collecting patient specific cost data.[12,15-19] Second, study team members from the NMDP's Patient Services department, who regularly interact with patients/caregivers applying for financial aid from the NMDP Patient Assistance Program provided input in the diary development process. The final instrument was paper based with rows representing various categories of out-of-pocket costs and columns for recording date and costs incurred.

The diary included a section that asked for the recipient's location (e.g., in hospital, in temporary lodging or at home) and whether the patient had a clinic visit each day. Expenses could be recorded under the following categories: (1) food (e.g., eating at a cafeteria, grocery purchases), (2) transportation (e.g., gas, tolls, parking, public transportation, air travel for visits to the transplant center), (3) medical expenses (e.g., co-payments for clinic visits and prescriptions and out-of-pocket expenses for medical supplies and any other medical services not covered by the patient's health insurance), (4) temporary lodging (e.g., rent, utilities), and (5) miscellaneous (e.g., childcare). Caregivers were instructed to report their out-of-pocket expenses even when the recipient was hospitalized.

During the study design phase, we considered whether or not to ask patients/caregivers to submit data to validate out-of-pocket costs (e.g., sales receipts, credit card statements). We elected not to require study participants to submit this information as we felt this would cause them undue burden during the emotionally and physically intense early post-transplant period.

Analysis

Descriptive statistics are reported for patient characteristics and out-of-pocket cost information. Qualitative data were collected via the baseline survey regarding patient and caregiver perception of the financial impact of HCT and questions asked in the diary evaluation interview.[20] Qualitative data were analyzed and summarized separately by five trained coders in accordance with standard procedures.[20-22] Coders met as a group to determine saturation of themes. When a difference in opinion occurred, it was discussed and resolved by consensus. Representative quotes are presented in this manuscript to support key themes and to show the diversity of opinions reported by study participants.

RESULTS

Patient Characteristics

Thirty patients were enrolled on this study in 2009 and 2010 at the three participating sites (Figure 1). The time between enrollment of first and last patient at the three sites was 5 months, 9 months and 14 months. Of the 30 patients, 5 did not complete the baseline survey. The characteristics of 25 patients/caregivers who completed the baseline survey are shown in Table 1. Supplemental table 1 compares the characteristics of patients who completed and did not complete the baseline survey. Although our study was open to both adult and pediatric HCT recipients, all enrolled patients were adults. Twelve (48%) patients/caregivers reported they would have to relocate to temporary housing close to the transplant center. Ten (40%) patients developed grade 2-4 acute graft-versus-host disease and 6 (24%) patients died during followup.

Pre-Transplant Financial Information

Table 2 summarizes responses of the 25 patients/caregivers who completed the baseline survey. The median pre-tax household income was $66,500. Household income had already been reduced due to the patient's illness in 80% of respondents and the majority reported that this decline had occurred within the year prior to transplantation. The patient was the primary and secondary wage earner in 7 and 9 households, respectively. Patients/caregivers planned to use a variety of resources to cover transplant related expenses such as use of disability income, use of vacation or sick days or paid time off, reliance on existing household income and on donations from family and friends. Twenty (80%) patients/caregivers expected the transplant to have a moderate or great impact on their household income and only 8 (32%) felt confident or very confident that they would be able to meet their household's financial obligations. The majority of patients (56%) had a managed care health insurance plan. Health insurance did not cover temporary lodging, meals or transportation for the majority of study participants.

Patient/Caregiver Perceptions of Financial Impact of Transplant

The baseline survey included open-ended questions that asked about patients/caregivers perceptions on how the transplant would impact their household finances over the short-term (6 months or less) and long-term (more than 6 months) after transplantation. For both time periods, some patients/caregivers perceived that the transplant would have a low impact while others felt it would have a great impact on household finances (Table 3). Availability of family/friend support and existing financial resources (e.g., savings, disability income, or presence of alternate wage earner) were dominant themes that were associated with patients/caregivers ability to cope with the short-term financial impact of transplantation. Patients/caregivers had concerns about the loss of household income with existing or increasing expenses during the transplant process. Uncertainty about the recovery process, fear of complications and ability to go back to work were the main issues perceived to be associated with their household's long-term financial health. Additional comments identified concerns about moving and living expenses for patients/caregivers who had to temporarily relocate, gaps in coverage or losing health insurance, uncertainty regarding financial recovery post-transplantation and emotional distress associated with household's financial situation.

Patient Out-of-Pocket Expenses

From the 25 patients/caregivers who completed the baseline survey, 22 submitted at least one diary, 20 submitted ≥ 4 diaries and 16 submitted all 6 diaries (Figure 1). The median total out-of-pocket costs reported by 20 patients/caregivers who completed ≥ 4 diaries were $2,440 (Table 4). There was a notable difference in out-of-pocket expenses among patients/caregivers who required relocation and temporary lodging and those who did not (median total costs were $5,247 vs. $716, Table 4 and Figure 2).

Study Evaluation

From the 22 patients/caregivers who submitted at least one diary, 18 completed the study evaluation interview. Overall satisfaction with the study processes and the out-of-pocket expense instrument was high. Fifteen (83%) respondents felt that it was 'very easy' or 'somewhat easy' to keep track of out-of-pocket expenses with the diary, 12 (67%) found tracking expenses to be helpful and 15 (83%) said that they would be willing to participate in a similar study in the future. Thirteen (74%) respondents reported that they felt 'comfortable' or 'somewhat comfortable' answering questions about income, 4 (22%) were 'neutral' and only 1 (6%) felt 'somewhat uncomfortable' about providing income information. Sixteen (89%) respondents felt 'comfortable' or 'somewhat comfortable' in answering questions about expenses and the other two (11%) felt 'neutral' about providing expense data. On average, it took 22 minutes daily to complete the diary entries.

Qualitative analysis showed that the patients/caregivers generally found the diary easy to use and helpful for tracking spending, increasing awareness of expenses, and improving communication about expenses between the caregiver and other family members. Suggestions for improving the diary included developing a web-based instrument and clarifying some instructions. Some study participants noted the daily time required to complete the diary as a challenge to submitting the diaries in a timely manner.

DISCUSSION

Our study demonstrates the feasibility of collecting patient/caregiver reported out-of-pocket cost information related to allogeneic HCT using a diary instrument over the first three months post-transplantation. Our pilot study data also show that some patients and their families can incur significant out-of-pocket expenses during this time period. Most patients/caregivers have concerns about the short-term and long-term impact of transplantation on household finances and lack confidence that they will be able to meet their financial obligations. These preliminary findings highlight the need for more research on the financial implications of transplantation from a patient's perspective.

Patient/caregiver feedback confirmed the feasibility of using our diary instrument for capturing out-of-pocket costs. Patients/caregivers in general were willing to provide information on income and expenses. However, we observed some challenges in conducting a patient level study of out-of-pocket costs. To better capture expenses, we required patients and their caregivers to reside in the same household. During the course of our study, we recognized that the definition of patient 'household' can be dynamic during the transplant

process. Because substantial caregiver effort can be required post-transplantation, households often get temporarily reorganized (e.g., sibling or parent may move in with the patient). Also, individuals outside of the immediate family such as relatives and friends frequently contribute to the caregiving effort and capturing out-of-pocket expenses in such circumstances can be challenging. Caregivers can find it emotionally difficult to complete the daily diary when patients experience serious complications. Finally, considerable effort was involved on the part of the study coordinators in calling study participants during the study. However, this effort did translate into a relatively high compliance rate compared to other investigations of out-of-pocket costs among oncology patients.

Notwithstanding the pilot study design and the small number of patients enrolled, our study highlights several important patient/caregiver financial issues in the early post-transplant period that need more comprehensive research. Patient/caregiver factors that may influence out-of-pocket costs need to be identified. We observed that patients/caregivers who had to temporarily relocate to lodgings close to the transplant center incurred substantially higher out-of-pocket expenses compared to those who did not have to move from their primary residence. At the same time, health insurance generally did not cover or provided limited coverage for costs related to temporary lodging, meals and transportation. Identification of total out-of-pocket costs and their predictors may be of interest to payors as they consider transplant coverage benefits, as inclusion of coverage for these expenses would significantly alleviate the financial stress that patients/caregivers face through the transplant process.

Our study highlights the variability and the need for more research to understand the financial experiences of patients/caregivers. Their own social and financial resources and coping skills as well as the resources provided by the transplant center can influence the impact transplantation has on the financial health of patient's/caregiver's household. A near universal theme identified pre-transplantation was the loss of household income with the potential for increasing household expenses in the setting of uncertainty about the recovery process. As can be expected, there were differences noted in the ability of patients/caregivers to cope with the financial stress of treatment based on their age, socioeconomic status and existing financial obligations. These findings emphasize the need for transplant centers to routinely incorporate a baseline assessment of patient finances as part of pre-transplant evaluation. Although the generalizability of our findings is limited by the small number of participating patients and centers, our study may help centers inform patients about the financial resources required as they plan for the transplantation procedure.

Certain limitations of our study have to be considered. The annual median household income of our study participants was higher than the national median household income in 2010 ($66,500 vs. $49,445). Socioeconomic status can be a barrier to access to transplantation and our cohort only reflects patients who were referred for HCT.[23] Furthermore, ethnic and racial minorities were underrepresented in our study. However, our study did include patients from a wide range of socioeconomic strata. We did not validate expenses as we felt it would be very burdensome for the patients/caregivers to submit receipts during the medically intense post-transplant recovery period. We did not address indirect costs such as lost wages and productivity for patients and for caregivers. We may have underestimated out-of-pocket costs as we could not account for certain expenses (e.g.,

medical bills that patients received after the study period) and for costs incurred by caregivers who were not members of the patients household (e.g., friends). Also, we may have enrolled fewer sicker patients given the commitment required for our study. Finally, our results are specific to the US and may not be generalizable to other countries.

Several unaddressed questions need further research such as the patient/caregiver out-of-pocket costs in the larger context of total costs of transplantation, influence of financial stressors on quality of life and recovery after transplantation, out-of-pocket costs associated with outpatient transplantation and with transplant complications such as chronic graft-versus-host disease, and the long-term financial impact of allogeneic transplantation on patients and their families. Our study lays the foundation for a future larger investigation of patient/caregiver out-of-pocket expenses associated with allogeneic HCT. We also highlight the relatively high patient/caregiver out-of-pocket costs associated with this treatment that may not be well appreciated by patients, caregivers, transplant centers and payors.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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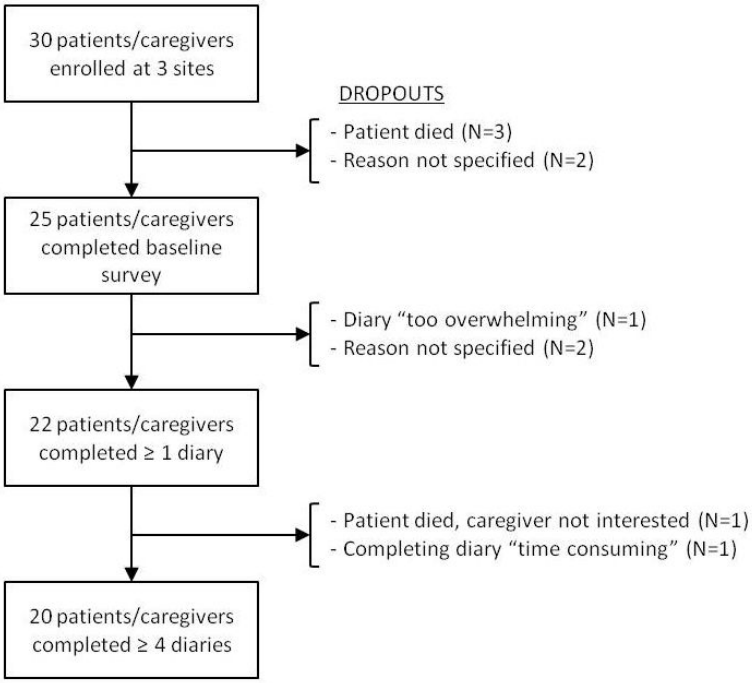

Figure 1.
Patient enrollment schema and reasons for dropout

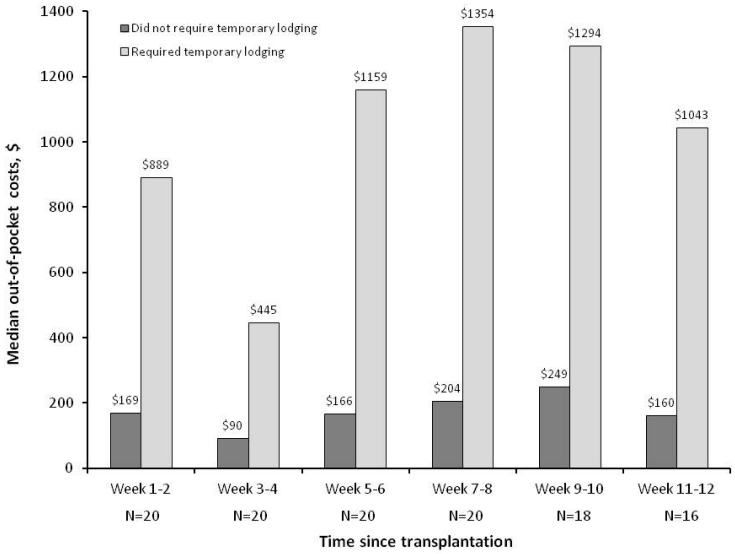

Figure 2.

Median out-of-pocket expenses by time post-transplantation for patients/caregivers who required and did not require temporary lodging (data shown for 20 patients/caregivers who submitted ≥ 4 of the 6 diaries)

Table 1

Baseline demographic characteristics of recipients who completed the baseline survey

Characteristic	N (%)
Number of patients	25
Age	
19-30 years	4 (16)
31-49 years	9 (36)
50-64 years	9 (36)
≥ 65 years	3 (12)
Gender	
Female	12 (48)
Male	13 (52)
Ethnicity/race	
Non-Hispanic White	24 (96)
Hispanic White	1 (4)
Diagnosis	
Acute myeloid leukemia	12 (48)
Acute lymphoblastic leukemia	6 (24)
Myelodysplastic syndrome	4 (16)
Other	3 (12)
Karnofsky performance score	
≥ 90	11 (44)
< 90	12 (48)
Missing	2 (8)
Co-existing disease*	
Yes	21 (84)
No	3 (12)
Missing	1 (4)
Donor type	
HLA-identical sibling	10 (40)
Matched unrelated donor	13 (52)
Unrelated umbilical cord blood	2 (8)
Graft source	
Bone marrow	7 (28)
Peripheral blood stem cells	16 (64)
Umbilical cord blood	2 (8)
Conditioning regimen intensity	
Myeloablative	13 (52)
Non-myeloablative/reduced-intensity	12 (48)
Marital status	
Married	18 (72)
Divorced	3 (12)

Characteristic	N (%)
Never married	3 (12)
Widowed	1 (4)
Education level	
High school or less	7 (28)
Some college/associate degree	7 (28)
Four year degree or higher	8 (32)
Distance from residence to transplant center	
< 50 miles	12 (48)
50-200 miles	10 (40)
> 200 miles	2 (8)
Not reported	1 (4)
Temporary move closer to transplant center	
Yes	12 (48)
No	12 (48)
Not reported	1 (4)

*Coexisting disease included pre-transplant history of cardiac or heart valve disease, arrhythmia, cerebrovascular disease, diabetes mellitus, hepatic disease, renal disease, infection, obesity, inflammatory bowel or peptic ulcer disease, rheumatologic disease, pulmonary disease, psychiatric disorder, prior solid cancer, hypertension or hypothyroidism

Table 2

Health insurance and household financial information of 25 patients/caregivers who completed the baseline survey

Characteristic	N evaluable*	N (%)
Current pre-tax annual household income, median (range)	22	$66,500 (30-375,000)
Annual pre-tax household income categories	22	
≤ $20,000		4 (18)
$20,001 – 60,000		6 (27)
$60,001 – 100,000		6 (27)
> $100,000		6 (27)
Number of wage earners in the household	24	
None		4 (17)
One		11 (46)
More than one		9 (37)
Patient is primary wage earner	24	7 (29)
Patient is secondary wage earner	23	9 (39)
Household income already reduced due to illness	25	20 (80)
Reduction in household income from diagnosis to transplant, median (range)	16	$15,690 (3,500-70,000)
Income reduction by current income categories, median (range)	16	
Current annual income ≤ $60,000		$15,800 (8,400-70,000)
Current annual income > $60,000		$15,300 (3,500-42,000)
When did reduction in household income begin	20	
< 6 months prior to HCT		9 (45)
6 months to 1 year prior to HCT		7 (35)
> 1 year prior to HCT		4 (20)
How will primary wage earners income be affected by the transplant	25	
Income will remain the same		9 (36)
Income will be reduced		7 (28)
Income will become zero because of job loss or unpaid leave of absence		7 (28)
Other, specify#		1 (4)
Decline to answer		1 (4)
Has household had to cash in retirement savings/other investments	25	
Yes		2 (8)
No		23 (92)
Has household had to declare bankruptcy	25	
Yes		0 (0)
No		25 (100)
Resources to be used to cover transplant-related expenses†	25	
Charity grants		2 (8)

Characteristic	N evaluable*	N (%)
Co-workers (donation of vacation/sick days)		3 (12)
Credit card		7 (28)
Disability income (including supplemental insurance)		17 (68)
Family/friend donations (not household members)		10 (40)
Fundraising		7 (28)
Household income		11 (44)
Retirement savings		5 (20)
Savings		8 (32)
Vacation or sick days/paid time off		12 (48)
Not sure/other		4 (16)
Estimated credit card debt, median (range)	17	$4,046 (200-20,000)
Primary health insurance	25	
Managed care (e.g., HMO or PPO plan)		14 (56)
Medicaid		5 (20)
Medicare		4 (17)
Major medical or catastrophic plan		2 (8)
Does health insurance have lifetime maximum	23	
Yes		8 (35)
No		8 (35)
Don't know		7 (30)
Lifetime maximum amount, median (range)	7	$2 million (1 million-5 million)
Does health insurance have annual deductible	23	
Yes		15 (65)
No		3 (13)
Don't know		5 (22)
Annual deductible amount, median (range)	11	$1,250 (500-4,000)
Does prescription plan have any limitations (e.g., need for pre-authorization)	23	
Yes		4 (17)
No		8 (35)
Don't know		11 (48)
Coverage for temporary lodging	22	
Full coverage		2 (9)
Limited coverage‡		5 (23)
No coverage		11 (50)
Don't know		4 (18)
Coverage for meals	24	
Full coverage		1 (4)
Limited coverage§		4 (17)
No coverage		15 (63)
Don't know		4 (17)
Coverage for transport	24	

Characteristic	N evaluable*	N (%)
Full coverage		0 (0)
Limited coverage//		4 (17)
No coverage		16 (67)
Don't know		4 (17)
Confidence in health insurance coverage for transplant related costs	23	
Very confident		9 (39)
Confident		6 (26)
Somewhat confident		6 (26)
Not at all confident		2 (9)
Expectation of how transplant will affect household income	25	
No impact		2 (8)
Minimal impact		1 (4)
Moderate impact		6 (24)
Great impact		14 (56)
Don't know		2 (8)
Confidence in meeting household's financial obligations	25	
Very confident		1 (4)
Confident		7 (28)
Somewhat confident		9 (36)
Not at all confident		8 (32)

*Excludes respondents who did not answer a specific question

#One patient reported that annual income would increase as disability income would be higher than present household income

†Respondents were allowed to choose multiple answers

‡For the 5 respondents, temporary lodging coverage was $10,000 time period not specified (N-=2), $10,000 per year (N=1), $200 per month (N=1) and $110 per day (N=1)

§For the 4 respondents, coverage for meals was $54 per day (N=1) and details not provided (N=3)

//For the 4 respondents, coverage for transportation was $10,000 time period not specified (N=1), 16 cents/mile driven (N=1) and details not provided (N=2)

Table 3

Representative comments highlighting patient/caregiver perceptions at baseline of short-term and long-term financial impact of allogeneic hematopoietic cell transplantation (N=25 respondents)

Question: How do you think the transplant will affect the household financially over the short term (6 months or less)?

Low impact (N=8)

- Impact should not be too great due to help of fund, family donations, sick/vacation time accrual; however, after funds used up there will be very real financial complications
- Minimal – will use up all savings as well as dip into retirement for travel, eating, lodging and such
- We should be okay because we have very good health insurance

High impact (N=16)

- It's a burden because I'm taking a cut in pay (on disability) and household expenses remain the same
- Will not have enough money to pay bills, other family members are using vacation time to help me and using their paychecks to help me
- I am the sole wage earner for the household, so losing my income will be devastating to the household
- Very much so, the patient has no sick time, he has long term disability that will pay 60% of wages after 3 months; spouse works two jobs, will only collect sick pay from one, will take a leave from other

Question: How do you think the transplant will affect the household financially over the long term (more than 6 months)

Low impact (N=4)

- I am somewhat confident that I will be able to pay bills, hopefully get off disability and pay my own way
- Both household members are very smart about saving money, so we just may have to save a little more in the future

High impact (N=16)

- It is hard to predict whether or not I will be able to go back to work and when; also, the amount of money that will be paid out in medical expenses; there is also the possibility that I would be readmitted to the hospital due to complications
- This is uncertain because I don't know if I will be able to return to work and I know my health insurance will terminate at 18 months
- We may have to file for bankruptcy, which not only hurts us now, but in the future because our credit scores will be affected making it even harder to meet living expenses
- Not well, the car will wear out from so many 200 mile one-way trips to (transplant center) – savings will all be gone

Table 4

Out-of-pocket expenses reported by patients and their caregivers over the first three months after allogeneic hematopoietic cell transplantation (data shown for 20 patients/caregivers who submitted ≥ 4 of the 6 diaries)*

Expenses§	All patients/caregivers, median (range)	Patients/caregivers who did not require temporary lodging, median (range)	Patients/caregivers who needed temporary lodging, median (range)
N	20	10	10
Days of hospital stay, median (range)	34 (22-82)	33 (22-82)	38 (25-78)
Number of clinic visits, median (range)	14 (0-32)	13 (0-32)	15 (4-23)
Average miles driven daily, median (range)	22 (2-96)	8 (2-41)	29 (4-96)
Total expenses	$2,440 (199-13,769)	$716 (199 - 2,210)	$5,247 (3,358 - 13,769)
Expense categories			
Food	$737 (47 – 3,253)	$390 (47 - 1,334)	$1,127 (385 - 2,702)
Transportation	$350 (25 - 2,609)	$171 (25 - 772)	$541 (75 - 2,396)
Medical expenses#	$508 (40 - 2,497)	$448 (40 - 1,351)	$821 (139 – 2,497)
Temporary lodging	$2,865 (238 - 6,607)†	--	$2,865 (238 - 6,607)
Other	$180 (8 - 3,752)	‡	$300 (30 - 3,752)

*22 patients submitted ≥ 1 diary; 2 patients submitted only 2 diaries covering the initial 4 week period post-transplantation and were excluded from this analysis

§Expenses reported by patients/caregivers; expenses were not adjusted for the Cost of Living Index (US Census Bureau), which was comparable for the three cities (Buffalo = 95.8, Milwaukee = 101.9 and Minneapolis = 111.0)

#Out-of-pocket medical expenses not covered by health insurance

†N=10 patients/caregivers who required temporary lodging

‡Two patients reported other expenses of $8 and $180 each