



Published in final edited form as:

*Bone Marrow Transplant.* 2016 September ; 51(9): 1233–1240. doi:10.1038/bmt.2016.103.

## Financial Impact of Allogeneic Hematopoietic Cell Transplantation on Patients and Families over 2-years: Results from a Multicenter Pilot Study

Ellen M. Denzen<sup>1</sup>, Viengneese Thao<sup>2</sup>, Theresa Hahn<sup>3</sup>, Stephanie J. Lee<sup>4</sup>, Philip L. McCarthy<sup>3</sup>, J. Douglas Rizzo<sup>5</sup>, Monique Ammi<sup>6</sup>, Rebecca Drexler<sup>6</sup>, Susan Flesch<sup>6</sup>, Heather James<sup>1</sup>, Nancy Omondi<sup>7</sup>, Elizabeth Murphy<sup>1</sup>, Kate Pederson<sup>1</sup>, and Navneet S. Majhail<sup>8</sup>

<sup>1</sup>National Marrow Donor Program, Minneapolis, MN

<sup>2</sup>School of Public Health, University of Minnesota, Minneapolis, MN

<sup>3</sup>Blood and Marrow Transplantation Program, Roswell Park Cancer Institute, Buffalo, NY

<sup>4</sup>Fred Hutchinson Cancer Research Center, Seattle, WA

<sup>5</sup>Center for International Blood and Marrow Transplant Research, Milwaukee, WI

<sup>6</sup>Center for International Blood and Marrow Transplant Research, Minneapolis, MN

<sup>7</sup>Robert D. and Patricia E. Kern Center for the Science of Health Care Delivery, Mayo Clinic, Rochester, MN

<sup>8</sup>Blood & Marrow Transplant Program, Cleveland Clinic, Cleveland, OH

### Abstract

Hematopoietic cell transplantation (HCT) is a procedure that can significantly influence the socioeconomic wellbeing of patients, caregivers and their families. Among 30 allogeneic HCT recipients and their caregivers enrolled on a pilot study evaluating the feasibility of studying financial impact of HCT, 16 agreed to participate in the long-term phase, completed a baseline questionnaire and received phone interviews at 6, 12, 18 and 24 months post-HCT. Analyses showed that by 2-years post-HCT, 54% of patients who previously contributed to household earnings had not returned to work and 80% of patients/caregivers reported transplant as having moderate to great impact on household income. However, patients' level of confidence in their ability to meet household financial obligations increased from baseline to 2-years. A relatively large proportion of patients reported inability to pay for medical care through this time period. Case studies demonstrated patient individual perception of financial impact of HCT varies considerably, regardless of actual income. We demonstrate the feasibility of conducting a study to evaluate financial impact of allogeneic HCT through 2-years post-transplantation. Some patients/caregivers continue to experience significant long-term financial burden after this procedure. Our

---

Users may view, print, copy, and download text and data-mine the content in such documents, for the purposes of academic research, subject always to the full Conditions of use: [http://www.nature.com/authors/editorial\\_policies/license.html#terms](http://www.nature.com/authors/editorial_policies/license.html#terms)

Corresponding Author: Navneet Majhail, MD, MS, Blood & Marrow Transplant Program, Cleveland Clinic, 9500 Euclid Ave, R35, Cleveland, OH 44139, majhain@ccf.org, Phone: 216-444-2199.

**Conflict of Interest Statement:** None of the authors has a relevant conflict of interest to disclose

study lays the foundation for a larger evaluation of patient/caregiver financial burden associated with HCT.

### Keywords

Hematopoietic stem cell transplantation; financial burden; patient costs; socioeconomic wellbeing

---

## INTRODUCTION

Hematopoietic cell transplantation (HCT) has the potential to adversely affect the socioeconomic wellbeing of patients and their families.<sup>1-4</sup> It is a highly specialized procedure that is available at select centers in the United States, such that patients and their caregivers frequently have to temporarily relocate to be close to a transplant center. Patients and caregivers often need to take an extended break from employment for pre-transplant treatments, transplantation and during the post-transplant recovery period. Routine household costs persist in this setting of lost wages and are compounded by direct and indirect healthcare-related costs such as insurance premiums, copays and deductibles, and costs associated with travel or relocation closer to a transplant center.

The financial impact of HCT on patients, families and caregivers has been inadequately studied. A few publications have reported out-of-pocket costs that are incurred by patients and their caregivers in the early post-transplant period.<sup>5-8</sup> In a previous report we have described patient and caregiver out-of-pocket costs, collected using patient and caregiver diaries, in the first three months after allogeneic HCT.<sup>5</sup> That article detailed costs collected from patient and caregiver diaries. The median out-of-pocket expenses during this time period were \$2,440 and patients and caregivers who required temporary lodging reported higher expenses compared to those who did not. The impact of HCT on long-term financial consequences is even less known. Khera, et al. have recently reported a study where they surveyed allogeneic HCT recipients from a single center to evaluate the financial burden of transplantation.<sup>9</sup> Seventy-three percent of respondents indicated that their cancer had hurt them financially and 47% reported that they had experienced some form of financial burden, such as decrease in household income by >50%, selling/mortgaging their home or withdrawing money from retirement savings.

This pilot study was conducted to evaluate the feasibility of prospectively capturing information from allogeneic HCT recipients and their families on out-of-pocket costs during the first three months and the long-term financial impact from three months to two years post-transplantation. Results of the early post-transplant out-of-pocket costs phase, where patients maintained a cost diary, have been previously published.<sup>5</sup> This article reports the long-term follow-up and demonstrates the feasibility of collecting data on the financial impact of HCT over a two year time period. We also describe the changes in financial wellbeing that occurred in households of patients who participated in the study and present descriptive case studies to highlight the variety of financial experiences that HCT patients and their caregivers face during this time period.

## MATERIALS AND METHODS

### Patients

Patient eligibility criteria and study design have been described previously.<sup>2</sup> Briefly, three transplant centers participated in this pilot study (Medical College of Wisconsin, Roswell Park Cancer Institute and University of Minnesota) and enrolled ten patients each. Patients undergoing first allogeneic HCT with any diagnosis, any graft/donor source and any conditioning regimen were eligible provided they had a caregiver who was a member of the patients' household. Since our study focused on financial issues specific to HCT, we restricted our eligibility criteria to patients who were within two years of diagnosis of their underlying disease. We also excluded patients who had previously received a transplant and patients from households where another family member had received a transplant. Patients had to be fluent in English to participate. The study was conducted under the guidance of Institutional Review Boards of the National Marrow Donor Program and the three participating transplant center sites. Both the patient and the caregiver provided informed consent before transplantation and caregivers were given the option to continue on the study in the event of the patient's death.

### Study Design

Patients and caregivers participating in this study completed a 65-item baseline questionnaire pre-HCT that obtained comprehensive information on their household's finances. They subsequently completed and submitted a cost-diary every two weeks to the study coordinating center at the Center for International Blood and Marrow Transplant Research (CIBMTR) through three months post-transplantation. The results of the out-of-pocket phase portion of our pilot study have been reported previously.<sup>5</sup> A phone interview was conducted at three months post-transplantation to obtain their feedback on the cost diary. At that time, they were also invited to continue on the long-term phase. Patients and caregivers who agreed to participate in the long-term phase received phone interviews at 6, 12, 18 and 24 months post-HCT. Study participants received a \$35 gift card for each interview completed. Data on patient and transplant characteristics were obtained from the CIBMTR database.

Interviews were conducted by phone by a research coordinator at the CIBMTR using a computer assisted telephone interview script and lasted for 15–20 minutes each. Either the patient or the caregiver could complete the interview. After initial introductory questions, including an inquiry of patient status, the interviewer asked questions with structured options that the respondent could choose from. These included questions on their present location (home vs. temporary relocation to closer to transplant center), household wage earners (number of earners and primary and secondary earner), total household income, any change in income since last interview, bankruptcy related to medical issues, and financial accounts used to cover expenses.

**Measurement of Financial Impact**—Respondents were asked to use Likert scales to rate how the transplant had affected their household income (no impact to great impact) and their confidence in meeting their household's financial obligations (not at all confident to

very confident). In addition, open ended questions asked patients/caregivers to describe how the transplant had affected their household financially, how the transplant will affect their household financially over the next 6 months and any other comments about their household financial situation. Responses were recorded and then transcribed for qualitative analyses.

The interviewer also asked the patient to complete the socioeconomic wellbeing scale.<sup>10</sup> This scale includes 17 items and was developed and validated to measure socioeconomic wellbeing in cancer patients. Respondents were asked to rate their agreement with statements on a five-point Likert scale, reporting how true each statement had been for them within the preceding 7 days. Examples include “I believe that being sick will hurt me financially,” “I am able to make enough money to pay for my healthcare,” “I am able to pay my medical bills,” “I have enough money to take care of my healthcare needs,” “I can get the health insurance I need,” and “The medicine I need is too expensive for me.” Only patients were asked to complete this instrument. The scale was completed at baseline (pre-transplant) by all patients and by 12, 13, 12 and 10 patients at the 6, 12, 18 and 24 month follow-up, respectively.

## Analysis

The primary aim of our study was to evaluate the feasibility of collecting information on long-term financial impact of allogeneic HCT and to pilot our data collection instruments. To establish feasibility, we specified *a priori* that >50% of patients/caregivers approached would continue on to the long-term follow-up phase of the study. Interviewers also monitored interviews to identify any questions that the patients/caregivers had difficulty answering and also noted the number of attempts it took to schedule and conduct the phone interviews.

Descriptive statistics are reported for patient characteristics and patient and caregiver responses. Responses to open ended questions were analyzed using qualitative methods. Two trained coders independently analyzed and summarized responses using standard procedures.<sup>11–13</sup> Coders then met as a group to determine saturation of themes and any differences in opinion were discussed and resolved by consensus. The manuscript presents representative quotes to support key themes and to show the diversity of opinions reported by patients and caregivers.

In order to inform the design of a larger study, we also conducted a phone focus group of the study coordinators at the three sites to understand any barriers and challenges towards recruiting and enrolling patients on the financial impact study in general. Focus group discussion was analyzed using qualitative methods described above. Data are also presented on the number of attempts it took for interviewers to contact the patients and caregivers for conducting the phone interview.

## RESULTS

### Patients

Of the 30 patients enrolled pre-HCT, 25 completed the three month out-of-pocket diary phase of the study. From these patients, 16 patients/caregivers agreed to continue on the

long-term phase. Table 1 describes the patient and transplant characteristics of the 16 study participants who are included in this analysis and the 9 patients/caregivers who were potentially eligible at the 3 month follow-up time point but did not continue onto the long-term phase. Pre-transplant financial information for these patients is also shown. The groups (diary phase vs. long-term phase) were comparable with the exception of household income and conditioning regimen intensity; myeloablative conditioning was used in a significantly larger proportion of patients enrolling on the long-term phase versus the diary phase. The household income of long-term phase participants was higher than patients who did not continue on the study (median annual household income was \$80,400 vs. \$43,000). The number of patients enrolled on the long-term phase by site were 9 from Roswell Park Cancer Institute, 5 from Medical College of Wisconsin, and 2 from University of Minnesota.

Acute GVHD occurred in 10 (63%) patients (grade 1 in 3, grade 2 in 4 and grade 3 in 3 patients) and chronic GVHD was reported in 9 (56%) patients. During the 2 years of follow-up, 7 (44%) patients experienced disease relapse or progression. Four patients died during this time period (1 each between 3–6 month and 6–12 month interviews and 2 between 12–18 month interviews). However, caregivers for 3 of the deceased patients elected to continue on the study. The causes of death for these 4 patients were disease relapse (N=3) or organ failure (N=1).

### **Study Feasibility, Strategies for Recruitment and Challenges to Enrollment**

Overall, 53% (16/30) of all enrolled patients/caregivers and 64% (16/25) of potentially eligible patients/caregivers who had completed the 3 month diary phase continued on the long-term study phase. This met our *a priori* criterion for demonstrating the feasibility of conducting a study of the financial impact of allogeneic HCT till 2 years post-transplantation. The majority of these 16 patients/caregivers completed the 2-year follow-up; interviews at 6, 12, 18 and 24 months were completed by 13 (81%), 15 (94%), 15 (94%) and 14 (88%) patients/caregivers, respectively.

In order to contact, schedule and conduct the interview, interviewers had to make a median of 1 phone contact at 6 months and 2 contacts at 12, 18 and 24 month time points. Each interview required approximately 15 minutes to complete. Based on the interviewer assessment, patients/caregivers were able to answer questions without any problems. The phone survey asked about approximate household annual income (excluding any Social Security income), and patients/caregivers in general were willing to provide this information. This question was completed by 14/16 (88%) respondents at baseline, 12/16 (75%) at 6 months, 15/16 (94%) at 12 months, 14/16 (88%) at 18 months and 14/16 (88%) at 24 months.

Site coordinators at all three locations were the primary individuals who screened and consented patients/caregivers for the study. They suggested that the best time to approach and recruit patients was during pre-transplant work up (range: 1 week – 1 month pre-transplant) because: (1) recruiting participants during work-up gave patients ample time to review study documents, ask questions and feel comfortable with the study; (2) most patients were consented to other clinical studies during this same time; and (3) their caregiver was usually with them during work-up appointments. Engaging the caregiver was

felt to be important for successful enrollment as the caregiver was most likely going to be responsible for keeping track of financial spending related to transplant. Other themes that were identified on focus group interviews to facilitate enrollment included availability of a dedicated study coordinator, having a physician champion for the study, and obtaining buy in from other physicians at the transplant program. The reasons cited for patients withdrawing from the study were varied, and no specific theme was identified.

Patients stated “not being interested in research” as the main reason for declining to participate in the study. Another reason was “having good insurance coverage” and a perception that the transplant would not have any impact on their household finances. The study coordinators still encouraged patients with “good coverage” to participate and felt that better educational materials about the study would facilitate overcoming this barrier to enrollment. Patients participating in this study were asked to participate in both the early diary phase and the long-term phone interview phase. Maintaining a daily cost diary deterred some patients/caregivers from participating in the study, as they felt journaling would take too much time. Some patients had questions about the privacy and confidentiality of the data that would be captured as part of this study. However, in the experience of the study coordinators, this was not a major deterrent to enrollment.

### **Financial impact of HCT through 2 years post-transplant**

Although our main goal was to evaluate the feasibility of studying long-term financial impact of HCT, we describe below the household financial information obtained from our cohort of patients (N=15). One patient/caregiver pair only completed one interview during follow-up and was excluded from this analysis (patient died during the long-term follow-up phase of the study and the caregiver completed the 12 month interview only).

Notwithstanding the fact that pre-HCT therapies may influence household wage earner dynamics, the patient was the primary or secondary wage earner in 80% (12/15) of the households pre-transplant (Figure 1). At the 2 year follow-up, the patient was the primary or secondary wage earner in only 33% (5/15) households. After excluding patients who died, 5/11 patients (46%) had returned to work by 2 years post-transplant. In most instances, the spouse or another household member was the primary wage earner for the household both pre-HCT and at the 2-year follow-up time period.

Among the 15 patients/caregivers who participated in long-term phase, 7 (54%) reported at least some reduction in pre-tax annual income (Table 2). As can be expected, the household financial experience post-transplant varied by social circumstances and availability of other financial resources. For example, in one household that experienced a decrease in income, the patient was able to return to work and remained the primary wage earner but the spouse was laid off from her job. In other households, a decrease in income was due to the patient or spouse/caregiver not being able to return to work. Still in other households, the caregiver was the primary wage earner and had to take time off from work to take care of patient. We highlight 3 case studies to demonstrate variation in perception of the financial impact of HCT, regardless of actual income (Table 3).

## HCT Impact on Socioeconomic Well Being

Over time, the majority of patients continued to report that HCT had a significant impact on household income over time with 94% prevalence at baseline and 80% at 12 and 24 months (Figure 2). However, patients' level of confidence in their ability to meet household financial obligations increased between baseline and 24 months. Most often, patients/caregivers had to rely on personal savings to pay transplant-related expenses with a small number using IRAs and retirement savings as well. This is further detailed in Figure 4, in which patients reported higher levels of agreement with statements focused on their ability to pay for medical care.

## Discussion

Financial burden may present as a major barrier to transplantation for some patients.<sup>14</sup> Patients who are able to receive HCT, may struggle with the financial toxicity associated with long-term recovery and complications after transplantation.<sup>1-4, 9</sup> With increasing awareness of the financial impact of cancer treatments, there is a critical need to understand the short-term and long-term economic burden associated with HCT. Our study demonstrates that a significant proportion of patients continue to face financial challenges through at least 2 years post-transplantation.

Although the sample size of our pilot study was small, our observations on the long-term financial burden faced by allogeneic HCT recipients and their caregivers contribute to our understanding in this area and will facilitate future studies. A significant proportion of patients and their families continued to perceive HCT as having a major impact on household finances and reported 'financial toxicity' (as measured by the Socioeconomic Wellbeing Scale) until at least 2-years post-transplantation. Interestingly, their reported confidence level in their ability to meet household financial obligations increased during this time period. This may represent patient/caregiver recognition and acceptance of the 'chronicity' of their recovery process and its associated financial uncertainty. From a methodological perspective, longitudinal studies investigating financial impact of HCT may need to incorporate approaches to account for a shift in response assessment. We also found that the financial experience of each household is very unique before and after transplantation and, anecdotally, may not correlate well with known socio-demographic factors. Qualitative research methods are an important component of investigating costs of transplantation from a patient perspective as they can summarize individual patient experiences.<sup>2, 5</sup>

Return to work is an indicator of functional recovery for transplant survivors. In our study, only half of patients who were working pre-HCT were able to return to work by 2-years post-transplantation. Return to work post-transplant is a complex personal decision for patients. In a qualitative literature review of cancer survivor work experiences, Stergiou-Kita et al identified return to work to be a continuous process with some key factors relevant to successful re-employment, including underlying symptoms, work abilities, coping, motivation, family support, work-place support, professional support, type of work/demands and job flexibility.<sup>15</sup> Specifically for the HCT recipient population, Kirchhoff et al have proposed a similar model that considers cancer and treatment related factors, pre-HCT

demographic characteristics and physical functioning and mental health status during recovery.<sup>16</sup> Other studies in autologous and allogeneic HCT recipients have reported return to work rates of up to 84% in 5-year survivors and rates comparable to their general population peers by 10-years post-transplantation.<sup>16-19</sup>

Our study also shows the feasibility of conducting a phone-interview based evaluation to capture data on the financial impact of allogeneic HCT through 2-years post-transplantation. We highlight resources required, and identify challenges faced during recruitment and opportunities to enhance enrollment, to assist other investigators who may be planning studies in this area. Other designs to address patient household financial toxicity need to be explored in the context of HCT. These may include use of secondary data (e.g., claims data, tax records) so that patient burden for providing this information is minimized. Future designs also need to consider leveraging and integrating informatics and technology to optimize data collection and make patient reporting of financial toxicity more real time and efficient (e.g., using smartphone based patient reported assessments).

Study limitations include a small sample size, which was appropriate for the pilot study objectives, and the potential for recall bias in patient/caregiver household income reporting. Also, the annual income of patients who participated in the long-term phase was higher compared to patients who completed the diary phase only and did not continue on the study. Only 2 patients from one site (University of Minnesota) continued on the long-term phase. This site was the first to get activated and informed study enrollment procedures, which in turn facilitated recruitment and retention of patients at the other two sites. Our findings may not be generalizable and reflect the experience of the small number of patients who were enrolled at the three sites, especially since our cohort did not include pediatric patients, racial/ethnic minorities and non-English speakers. However, our study was designed to be a pilot feasibility study that would inform a larger investigation of financial toxicity in HCT recipients.

Despite these limitations, our study demonstrates the feasibility of collecting data over 2-years post-transplant on household income, financial status and socioeconomic wellbeing from patients/caregivers, highlights important themes on financial burden patients/caregivers face post-transplantation and lays the foundation for further research in the area of financial toxicity after HCT. While future studies in this area will increase our understanding about the predictors of and interventions to mitigate the adverse financial effects of HCT in vulnerable patients, our data highlights the immediate need for transplant centers to be aware of the profound negative impact HCT can incur on household finances for some patients. Social workers or psychosocial clinicians or related professionals can assist in identifying patients at high risk and can provide resources to patients and their caregivers for preventing and alleviating financial toxicity.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.



## Acknowledgments

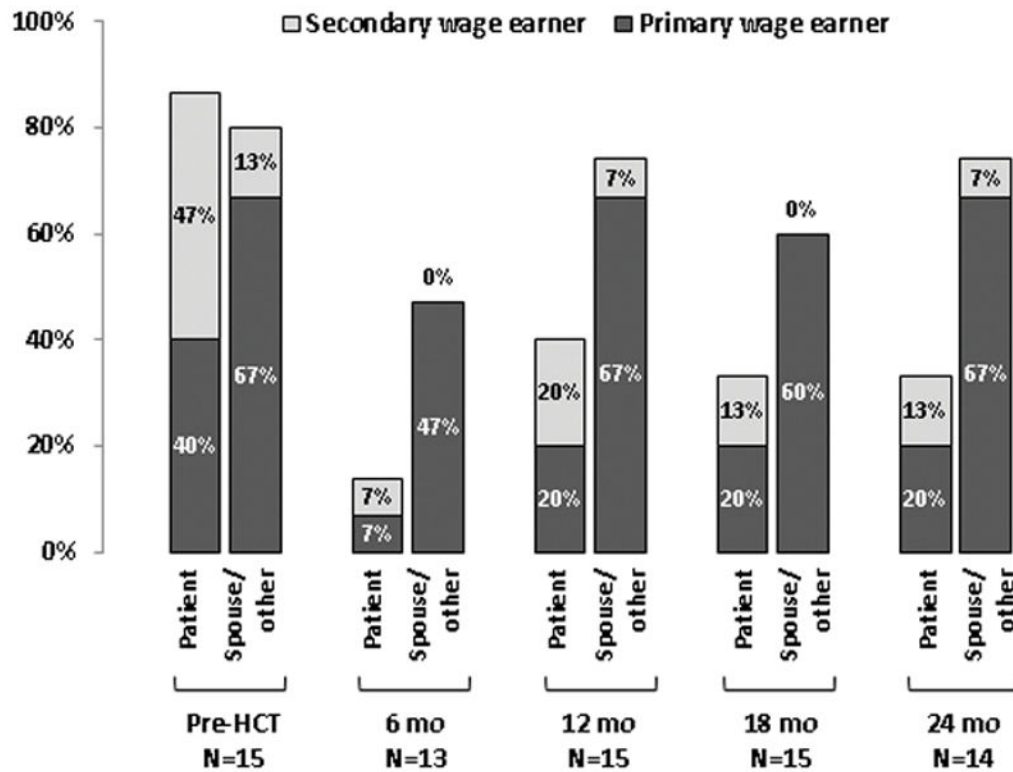
We would like to thank Tammy Payton and Lih-Men Mau, PhD, MPH, National Marrow Donor Program<sup>®</sup> (NMDP<sup>®</sup>)/Be The Match<sup>®</sup>, Patient and Health Professional Services department for assisting with the analysis of qualitative data. We thank the study coordinators at the Medical College of Wisconsin (Leigh Ann Laczkowski), Roswell Park Cancer Institute (Dana Cipolla, Lise Hernandez) and the University of Minnesota (Jenna Johnson) for their help in enrolling patients on the study. The NMDP provided funding for study participant honoraria.

The CIBMTR is supported by Public Health Service Grant/Cooperative Agreement U24-CA76518 from the National Cancer Institute (NCI), the National Heart, Lung and Blood Institute (NHLBI) and the National Institute of Allergy and Infectious Diseases (NIAID); a Grant/Cooperative Agreement 5U01HL069294 from NHLBI and NCI; a contract HHS234200637015C with Health Resources and Services Administration (HRSA/DHHS); two Grants N00014-06-1-0704 and N00014-08-1-0058 from the Office of Naval Research; and grants from Allos, Inc.; Amgen, Inc.; Angioblast; Anonymous donation to the Medical College of Wisconsin; Ariad; Be the Match Foundation; Blue Cross and Blue Shield Association; Buchanan Family Foundation; CaridianBCT; Celgene Corporation; CellGenix, GmbH; Children's Leukemia Research Association; Fresenius-Biotech North America, Inc.; Gamida Cell Teva Joint Venture Ltd.; Genentech, Inc.; Genzyme Corporation; GlaxoSmithKline; HistoGenetics, Inc.; Kiadis Pharma; The Leukemia & Lymphoma Society; The Medical College of Wisconsin; Merck & Co, Inc.; Millennium: The Takeda Oncology Co.; Milliman USA, Inc.; Miltenyi Biotec, Inc.; National Marrow Donor Program; Optum Healthcare Solutions, Inc.; Osiris Therapeutics, Inc.; Otsuka America Pharmaceutical, Inc.; RemedyMD; Sanofi; Seattle Genetics; Sigma-Tau Pharmaceuticals; Soligenix, Inc.; StemCyte, A Global Cord Blood Therapeutics Co.; Stemsoft Software, Inc.; Swedish Orphan Biovitrum; Tarix Pharmaceuticals; Teva Neuroscience, Inc.; THERAKOS, Inc.; and Wellpoint, Inc. The views expressed in this article do not reflect the official policy or position of the National Institute of Health, the Department of the Navy, the Department of Defense, or any other agency of the U.S. Government.

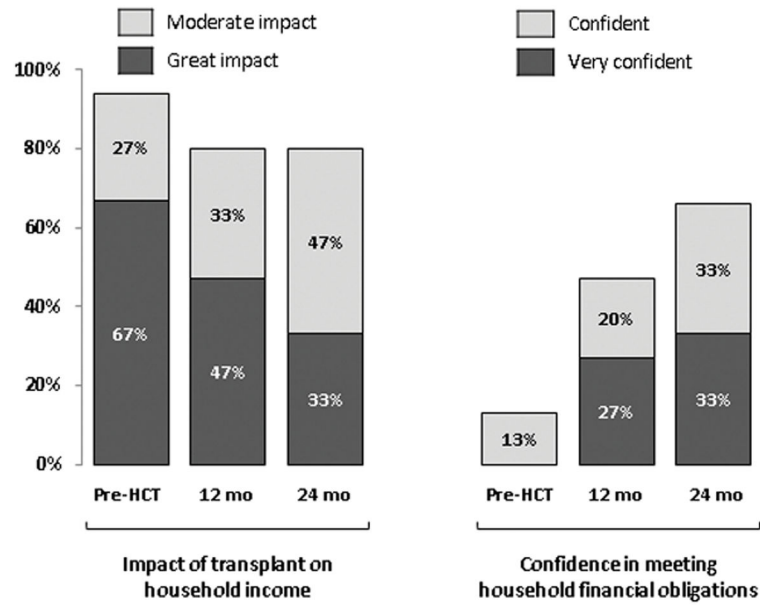
## References

1. Preussler JM, Denzen EM, Majhail NS. Costs and cost-effectiveness of hematopoietic cell transplantation. *Biol Blood Marrow Transplant*. 2012; 18(11):1620–8. [PubMed: 22484549]
2. Kim W, McNulty J, Chang YH, Weise M, Hashmi S, Ailawadhi S, et al. Financial burden after allogeneic hematopoietic cell transplantation: a qualitative analysis from the patient's perspective. *Bone marrow transplantation*. 2015 in press.
3. McNulty J, Khera N. Financial Hardship—an Unwanted Consequence of Cancer Treatment. *Current hematologic malignancy reports*. 2015 in press.
4. Khera N, Zeliadt SB, Lee SJ. Economics of hematopoietic cell transplantation. *Blood*. 2012; 120(8): 1545–51. [PubMed: 22700725]
5. Majhail NS, Rizzo JD, Hahn T, Lee SJ, McCarthy PL, Ammi M, et al. Pilot study of patient and caregiver out-of-pocket costs of allogeneic hematopoietic cell transplantation. *Bone marrow transplantation*. 2013; 48(6):865–71. [PubMed: 2322378]
6. Frey P, Stinson T, Siston A, Knight SJ, Ferdman E, Traynor A, et al. Lack of caregivers limits use of outpatient hematopoietic stem cell transplant program. *Bone marrow transplantation*. 2002; 30(11): 741–8. [PubMed: 12439696]
7. Meehan KR, Fitzmaurice T, Root L, Kintis E, Patchett L, Hill J. The financial requirements and time commitments of caregivers for autologous stem cell transplant recipients. *J Support Oncol*. 2006; 4(4):187–90. [PubMed: 16669462]
8. Rizzo JD, Vogelsang GB, Krumm S, Frink B, Mock V, Bass EB. Outpatient-based bone marrow transplantation for hematologic malignancies: cost saving or cost shifting? *J Clin Oncol*. 1999; 17(9):2811–8. [PubMed: 10561357]
9. Khera N, Chang YH, Hashmi S, Slack J, Beebe T, Roy V, et al. Financial burden in recipients of allogeneic hematopoietic cell transplantation. *Biol Blood Marrow Transplant*. 2014; 20(9):1375–81. [PubMed: 24867778]
10. Head BA, Faul AC. Development and validation of a scale to measure socioeconomic well-being in persons with cancer. *J Support Oncol*. 2008; 6(4):183–92. [PubMed: 18491687]
11. Burnard P. A method of analysing interview transcripts in qualitative research. *Nurse Educ Today*. 1991; 11(6):461–6. [PubMed: 1775125]
12. Krueger, RA.; Casey, MA. *Focus groups: A practical guide for applied research*. 3. Sage Publications; Thousand Oaks, CA: 2009.

13. Pope C, Ziebland S, Mays N. Qualitative research in health care. Analysing qualitative data. *BMJ*. 2000; 320(7227):114–6. [PubMed: 10625273]
14. Majhail NS, Omondi NA, Denzen E, Murphy EA, Rizzo JD. Access to hematopoietic cell transplantation in the United States. *Biol Blood Marrow Transplant*. 2010; 16(8):1070–5. [PubMed: 20036337]
15. Stergiou-Kita M, Grigorovich A, Tseung V, Milosevic E, Hebert D, Phan S, et al. Qualitative meta-synthesis of survivors' work experiences and the development of strategies to facilitate return to work. *Journal of cancer survivorship: research and practice*. 2014; 8(4):657–70. [PubMed: 24993807]
16. Kirchhoff AC, Leisenring W, Syrjala KL. Prospective predictors of return to work in the 5 years after hematopoietic cell transplantation. *Journal of cancer survivorship: research and practice*. 2010; 4(1):33–44. [PubMed: 19936935]
17. Syrjala KL, Langer SL, Abrams JR, Storer B, Sanders JE, Flowers ME, et al. Recovery and long-term function after hematopoietic cell transplantation for leukemia or lymphoma. *Jama*. 2004; 291(19):2335–43. [PubMed: 15150205]
18. Syrjala KL, Langer SL, Abrams JR, Storer BE, Martin PJ. Late effects of hematopoietic cell transplantation among 10-year adult survivors compared with case-matched controls. *J Clin Oncol*. 2005; 23(27):6596–606. [PubMed: 16170167]
19. Mosher CE, Redd WH, Rini CM, Burkhalter JE, DuHamel KN. Physical, psychological, and social sequelae following hematopoietic stem cell transplantation: a review of the literature. *Psycho-oncology*. 2009; 18(2):113–27. [PubMed: 18677717]

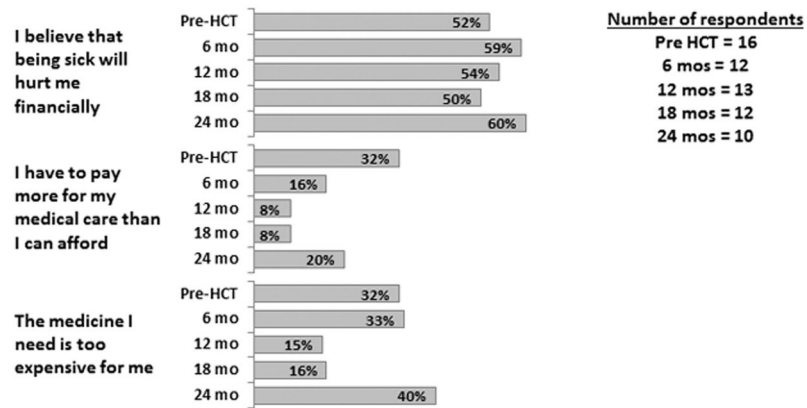


**Figure 1.** Proportion of patients and caregivers who were working as primary or secondary wage earners pre-transplantation and through 2 years post-transplantation (if applicable, both patients and caregivers could report themselves as primary wage earners)

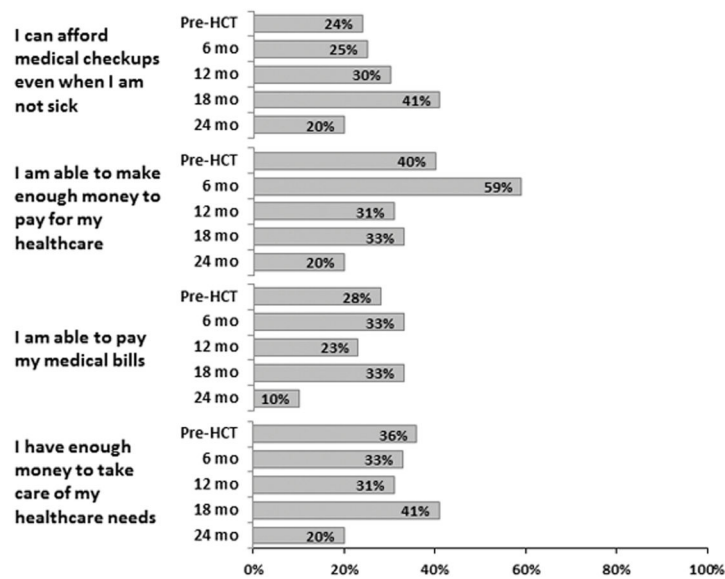


**Figure 2.** Impact of transplant on household income over time (left panel) and patient/caregiver confidence in meeting household financial obligations (right panel) (N=15 pre-HCT, 15 at 12 months, and 14 at 24 months)

**Proportion of patients responding “Quite a bit/very much”**



**Proportion of patients responding “Not at all/a little bit”**



**Figure 3.** Agreement with select Socioeconomic Wellbeing Scale items on financial issues experienced by cancer patients

**Table 1**

Transplant and patient household financial characteristics of 16 patients who participated in the long-term phase. Characteristics of 9 patients who completed the diary phase but did not continue on the long-term phase are also shown.

| <b>Patient Characteristics</b>           | <b>Long-term Phase<br/>N (%)</b> | <b>Diary Phase Only<br/>N (%)</b> |
|--|----------------------------------|-----------------------------------|
| Number of patients (N)                   | 16                               | 9                                 |
| <i>Transplant characteristics</i>        |                                  |                                   |
| Age at transplant, years                 |                                  |                                   |
| 19–30                                    | 2 (13)                           | 2 (22)                            |
| 31–49                                    | 8 (50)                           | 1 (11)                            |
| 50–64                                    | 5 (31)                           | 4 (45)                            |
| 65                                       | 1 (6)                            | 2 (22)                            |
| Gender                                   |                                  |                                   |
| Male                                     | 7 (44)                           | 6 (67)                            |
| Female                                   | 9 (56)                           | 3 (33)                            |
| Race/ethnicity                           |                                  |                                   |
| Non-Hispanic White                       | 16 (100)                         | 8 (89)                            |
| Hispanic White                           | -                                | 1 (11)                            |
| Diagnosis                                |                                  |                                   |
| Acute myeloid leukemia                   | 7 (44)                           | 5 (56)                            |
| Acute lymphoblastic leukemia             | 5 (31)                           | 1 (11)                            |
| Myelodysplastic syndrome                 | 2 (13)                           | 2 (22)                            |
| Other                                    | 2 (13)                           | 1 (11)                            |
| Donor type                               |                                  |                                   |
| HLA-identical sibling                    | 6 (38)                           | 4 (45)                            |
| HLA-matched unrelated                    | 10 (63)                          | 3 (33)                            |
| Unrelated cord blood                     | -                                | 2 (22)                            |
| Conditioning regimen*                    |                                  |                                   |
| Non-myeloablative/reduced intensity      | 4 (25)                           | 8 (89)                            |
| Myeloablative                            | 12 (75)                          | 1 (11)                            |
| Graft type                               |                                  |                                   |
| Bone marrow                              | 6 (38)                           | 1 (11)                            |
| Peripheral blood stem cells              | 10 (63)                          | 6 (67)                            |
| Umbilical cord blood                     | -                                | 2 (22)                            |
| <i>Socio-demographic characteristics</i> |                                  |                                   |
| Marital status                           |                                  |                                   |
| Married                                  | 14 (88)                          | 4 (45)                            |
| Divorced                                 | 2 (12)                           | 1 (11)                            |
| Never married                            | -                                | 3 (33)                            |
| Widowed                                  | -                                | 1 (11)                            |
| Education level                          |                                  |                                   |
| High school or less                      | 5 (31)                           | 2 (22)                            |

| <b>Patient Characteristics</b>                               | <b>Long-term Phase<br/>N (%)</b> | <b>Diary Phase Only<br/>N (%)</b> |
|--|----------------------------------|-----------------------------------|
| Some college/associate degree                                | 4 (25)                           | 5 (55)                            |
| Four year degree or higher                                   | 6 (38)                           | 2 (22)                            |
| Not reported   | 1 (6)                            | -                                 |
| Distance from primary residence to transplant center         |                                  |                                   |
| < 50 miles   | 7 (44)                           | 5 (56)                            |
| 50–200 miles   | 8 (50)                           | 2 (22)                            |
| > 200 miles  | -                                | 2 (22)                            |
| Not reported   | 1 (6)                            | -                                 |
| Temporary move closer to transplant center                   |                                  |                                   |
| Yes  | 10 (63)                          | 2 (22)                            |
| No   | 6 (37)                           | 7 (78)                            |
| <b><i>Pre-transplant household financial information</i></b> |                                  |                                   |
| Median annual pre-tax income (range)                         | \$80,400 (\$12,000–375,000)      | \$43,000 (\$9,120–\$150,000)      |
| Annual pre-tax income  |                                  |                                   |
| < \$40,000   | 4 (25)                           | 3 (34)                            |
| \$40,000–79,999  | 4 (25)                           | 2 (22)                            |
| 80,000   | 6 (38)                           | 2 (22)                            |
| Did not disclose   | 2 (13)                           | 2 (22)                            |
| Number of wage earners                                       |                                  |                                   |
| None   | 2 (13)                           | 2 (22)                            |
| One  | 8 (50)                           | 3 (33)                            |
| Two or more  | 6 (37)                           | 3 (33)                            |
| Not reported   | -                                | 1 (12)                            |
| Patient is primary wage earner                               | 6 (38)                           | 1 (11)                            |
| Patient is secondary wage earner                             | 7 (44)                           | 2 (22)                            |
| Primary health insurance                                     |                                  |                                   |
| Managed care (e.g., PPO or HMO plan)                         | 9 (56)                           | 5 (56)                            |
| Medicaid   | 3 (18)                           | 2 (22)                            |
| Medicare   | 2 (13)                           | 2 (22)                            |
| Other  | 2 (13)                           | -                                 |
| <b><i>Transplant outcomes</i></b>                            |                                  |                                   |
| Survival status alive at day 100                             | 16 (100)                         | 7 (78)                            |
| Acute GVHD by day 100  | 10 (63)                          | 6 (67)                            |

Change in patients' household income over 2 years (n=15). One patient/caregiver pair who completed only 1 interview during the long-term followup was excluded from analysis of financial impact.

**Table 2**

| Chronic GVHD by 2-yrs post-HCT | Patient primary or secondary wage earner |              | Annual household income <sup>‡</sup> |                   |
|--------------------------------|--|--------------|--------------------------------------|-------------------|
|                                | Pre-HCT                                  | At 24 months | Pre-HCT (\$)                         | At 24 months (\$) |
| No                             | Yes                                      | No           | 30,000                               | 21,600            |
| No                             | Yes                                      | No           | Not reported                         | 23,000            |
| No                             | Yes                                      | *            | 185,000                              | 150,000           |
| No                             | No                                       | *            | 103,000                              | 18,900            |
| No                             | Yes                                      | Yes          | 100,000                              | 100,000           |
| No                             | Yes                                      | *            | 65,000                               | Not reported      |
| Yes                            | Yes                                      | Yes          | 12,000                               | 29,400            |
| Yes                            | Yes                                      | No           | 42,000                               | 88,000            |
| Yes                            | No                                       | No           | 49,000                               | 51,000            |
| Yes                            | Yes                                      | No           | 21,800                               | 51,600            |
| Yes                            | Yes                                      | Yes          | 33,000                               | 20,400            |
| Yes                            | Yes                                      | Yes          | 105,000                              | 66,000            |
| Yes                            | Yes                                      | No           | Not reported                         | 42,000            |
| Yes                            | No                                       | No           | 76,000                               | 64,000            |
| Yes                            | Yes                                      | Yes          | 90,000                               | 44,400            |
|                                |  |              |                                      | 26,400            |
|                                |  |              |                                      | Not reported      |
|                                |  |              |                                      | 136,000           |
|                                |  |              |                                      | 65,000            |
|                                |  |              |                                      | 110,000           |
|                                |  |              |                                      | 14,400            |
|                                |  |              |                                      | 27,600            |
|                                |  |              |                                      | 83,600            |
|                                |  |              |                                      | 51,000            |
|                                |  |              |                                      | 36,000            |
|                                |  |              |                                      | 38,800            |
|                                |  |              |                                      | 78,000            |
|                                |  |              |                                      | 36,000            |
|                                |  |              |                                      | 36,000            |
|                                |  |              |                                      | 70,100            |

\* Patient died during the 2-year follow-up

<sup>‡</sup> Income excluding Social Security income (rounded to nearest 100's)



**Table 3**  
Representative case studies on the perceived financial impact of hematopoietic cell transplantation

|  | Baseline Factors   | Course of Treatment   | One Year Post-HCT  | Two Year Post-HCT  |
|--|--|---|--|--|
| <b>Scenario 1:<br/>Low Perceived Impact</b>    | <p>Patient is White female in her 20's, married with 2 young children. Did not disclose household baseline household income, but was reported to be reduced prior to HCT. Husband (primary wage earner) lost his job pre-HCT and patient could not work due to illness. They live &lt;50 miles from the transplant center, but will relocate temporarily for treatment. Patient has Medicaid which will cover temporary housing and meal costs. They report small savings and some credit card debt; disability and family/friends will help cover HCT expenses. They expect HCT to have a great impact on their household income and are not at all confident that they will meet their financial obligations.</p>  | <ul style="list-style-type: none"> <li>• AML</li> <li>• Unrelated allogeneic donor HCT using PBSC</li> <li>• &lt;1 month post HCT, developed grade 3 acute GVHD</li> <li>• 5 months post HCT, developed extensive chronic GVHD</li> </ul> | <p>Annual household income reported as \$42,000. Patient stated that she expects the impact of HCT on income will be minimal. Very confident that they will meet financial obligations.</p>  | <p>Annual household income reported as \$42,000. Patient stated that HCT impact on household income has been minimal. Remains confident that they will meet their financial obligations.</p>   |
| <b>Scenario 2:<br/>Medium Perceived Impact</b> | <p>Patient is White male in his 30's, married with 2 young children. Baseline household income is \$143,000. There are 2 wage earners in the household, patient (primary) and his wife (caregiver; secondary). Patient lives 100–200 miles from the transplant center and will temporarily relocate for treatment. Patient is privately insured, has a \$500 annual deductible, co-pays of \$20–50 per prescription/visit, \$10,000 benefit for meals and lodging and \$0.24/mile for travel. They have savings; and resources to cover treatment expenses including: disability income, family/friends, household income, retirement, savings, and PTO. They expect HCT to have a moderate impact. They are somewhat confident that they will meet their financial obligations.</p> | <ul style="list-style-type: none"> <li>• AML</li> <li>• Related allogeneic donor HCT using PBSC</li> <li>• Relapsed 5 months post HCT</li> <li>• Patient died at 14 months post HCT</li> </ul>  | <p>Patient is not working. Annual household income reported as \$150,000. Financial impact of HCT is moderate. "We feel fortunate to have a job with good benefits." They are confident that they will meet their financial obligations.</p>   | <p>Annual household income is \$136,000. Transplant has had a moderate impact on finances. After death of patient, wife (caregiver) relocated to be closer to family and will be starting a new job. "Death of husband impacted everything." Caregiver is confident that she will meet her financial obligations.</p>  |
| <b>Scenario 3:<br/>High Perceived Impact</b>   | <p>Patient is White female in her 30's, married with 2 young children. She is the sole wage earner for the family. Baseline household income is \$30,000 but will go to \$0 due to unpaid leave. Patient lives 100–200 miles from the transplant center and will temporarily relocate for treatment. Patient is privately insured and receives Medical Assistance. Insurance does not include benefits for lodging, meals or travel. They have minimal savings, and will rely on disability income. Family/friends will help with child care. They expect HCT to have a great impact on their income and are not at all confident they will be able to meet their financial obligations.</p>   | <ul style="list-style-type: none"> <li>• AML</li> <li>• Unrelated allogeneic donor HCT using BM</li> <li>• 3 months post HCT, developed grade 3 acute GVHD</li> <li>• 2 years post-HCT, developed limited chronic GVHD</li> </ul>         | <p>Annual household income reported as \$20,000. Returning to work part-time hurt the family financially as patient became ineligible for Food Share program. She stressed that "I'm still on 22 medications. This really adds up." Paying 2 health insurance premiums adds to financial hardship. "Impact still overwhelming." Somewhat confident they will meet financial obligations.</p> | <p>Patient returned to work FT but had missed opportunities to advance career which, "stunted us financially." Annual household income is \$39,000. Patient on payment plan to reimburse employer for health insurance while on leave. HCT had a great impact on income and only somewhat confident in ability to meet financial obligations. While the financial situation was improving, the HCT experience scarred the family in other ways (psychological toll).</p> |

HCT – hematopoietic cell transplantation; AML – acute myeloid leukemia; PBSC – peripheral blood stem cells; GVHD – graft-versus-host disease; PTO – paid time off