Biol Blood Marrow Transplant 25 (2019) 599–605

Biology of Blood and
Marrow Transplantation

journal homepage: www.bbmt.org

ASBMT
American Society for Blood
and Marrow Transplantation

Analysis

Employment, Insurance, and Financial Experiences of Patients with Chronic Graft-versus-Host Disease in North America

Nandita Khera[1,*], Betty K. Hamilton[2], Joseph A. Pidala[3], William A. Wood[4], Vicky Wu[5], Jenna Voutsinas[5], Lynn Onstad[5], Amin M. Alousi[6], Raewyn Broady[7], George L Chen[8], Mukta Arora[9], Corey Cutler[10], Mary E. Flowers[5], Alex Ganetsky[11], Madan Jagasia[12], Philip L. McCarthy[8], Stefanie Sarantopoulos[13], Gregory A. Abel[10], Navneet S. Majhail[2], Stephanie J. Lee[5]

[1] *Division of Hematology and Medical Oncology, Department of Medicine, Mayo Clinic Arizona, Phoenix, Arizona*
[2] *Blood and Marrow Transplantation, Department of Hematology and Medical Oncology, Taussig Cancer Institute, Cleveland Clinic, Cleveland, Ohio*
[3] *Blood and Marrow Transplantation, H. Lee Moffitt Cancer Center and Research Institute, Tampa, Florida*
[4] *Division of Hematology/Oncology, University of North Carolina, Chapel Hill, North Carolina*
[5] *Clinical Research Division, Fred Hutchinson Cancer Research Center, Seattle, Washington*
[6] *The University of Texas M.D. Anderson Cancer Center, Houston, Texas*
[7] *Leukemia/Bone Marrow Transplant Program of British Columbia, BC Cancer Agency, Vancouver, British Columbia, Canada*
[8] *Department of Medicine, Roswell Park Cancer Institute, Buffalo, New York*
[9] *Hematology, Oncology and Transplantation, University of Minnesota, Minneapolis, Minnesota*
[10] *Division of Medical Oncology, Dana-Farber Cancer Institute, Boston, Massachusetts*
[11] *Hematology/BMT, University of Pennsylvania, Philadelphia, Pennsylvania*
[12] *Division of Hematology/Oncology, Vanderbilt-Ingram Cancer Center, Nashville, Tennessee*
[13] *Division of Hematologic Malignancies and Cellular Therapy, Department of Medicine, Duke University, Durham, North Carolina*

Article history:
Received 15 August 2018
Accepted 28 September 2018

Key Words:
Financial hardship
hematopoietic cell
transplantation
chronic GVHD

ABSTRACT

Understanding the socioeconomic impact of chronic graft-versus-host disease (GVHD) on affected patients is essential to help improve their overall well-being. Using data from the Chronic GVHD Consortium, we describe the insurance, employment, and financial challenges faced by these patients and the factors associated with the ability to work/attend school and associated financial burdens. A 15-item cross-sectional questionnaire designed to measure financial concerns, income, employment, and insurance was completed by 190 patients (response rate, 68%; 10 centers) enrolled on a multicenter Chronic GVHD Consortium Response Measures Validation Study. Multivariable logistic regression models examined the factors associated with financial burden and ability to work/attend school. The median age of respondents was 56 years, and 87% of the patients were white. A higher proportion of nonrespondents had lower income before hematopoietic cell transplantation and less than a college degree. All but 1 patient had insurance, 34% had faced delayed/denied insurance coverage for chronic GVHD treatments, and 66% reported a financial burden. Patients with a financial burden had greater depression/anxiety and difficulty sleeping. Nonwhite race, lower mental functioning, and lower activity score were associated with a greater likelihood of financial burden. Younger age, early risk disease, and higher mental functioning were associated with a greater likelihood of being able to work/attend school. In this multicenter cohort of patients with chronic GVHD, significant negative effects on finances were observed even with health insurance coverage. Future research should investigate potential interventions to provide optimal and affordable care to at-risk patients and prevent long-term adverse financial outcomes in this vulnerable group.

INTRODUCTION

Financial hardship as a result of cancer diagnosis and treatment is a well-recognized challenge for patients and health-care providers and has been associated with increased distress and poor quality of life [1–4]. Several studies have explored financial burden as reflected by decreased income, high out-of-pocket costs/medical bills, and adverse impacts on lifestyle/treatment owing to the cost burden in patients who have undergone hematopoietic cell transplantation (HCT), even though most have insurance coverage [5–8].

Chronic graft-versus-host disease (GVHD) is an important complication after allogeneic HCT that contributes to the long-term morbidity and mortality from the procedure [9–12].

Financial disclosure: See Acknowledgments on page 605.

[*] Correspondence and reprint requests: Nandita Khera, MD, MPH, Mayo Clinic, 5777 E Mayo Boulevard, Phoenix, AZ 85054.

E-mail address: khera.nandita@mayo.edu (N. Khera).

https://doi.org/10.1016/j.bbmt.2018.09.040
1083-8791/

There is a growing concern about the long-term social and financial implications of chronic GVHD because of the need for intensive, prolonged medical follow-up/treatments and impaired functional status, preventing return to work.

The multi-institutional cohort of patients with chronic GVHD assembled by the North American Chronic GVHD Consortium for the validation of response measures (n = 383) provides a valuable and unique opportunity to study these aspects of psychosocial outcomes of chronic GVHD. Understanding the impact of financial burdens on individuals with chronic GVHD can help identify at-risk patients, mitigate the distress associated with the disease, and improve the overall well-being of these patients. The extensive clinical, sociodemographic, and patient-reported outcome information collected through the parent study provides a rich context for understanding the financial burden and related issues, such as insurance and employment, for these patients. We supplemented the data already collected as part of the parent study with a cross-sectional questionnaire to obtain and report information about financial concerns, income, employment, and insurance for these patients.

METHODS

Patients

The Chronic GVHD Consortium Response Measures Validation Study is a prospective, multicenter observational study that collects data on a cohort of HCT recipients with chronic GVHD [13]. Patients enrolled in the cohort are allogeneic HCT recipients with a diagnosis of chronic GVHD who initiated a new systemic treatment for chronic GVHD within 4 weeks before or after enrollment. Exclusion criteria included primary disease relapse and the inability to comply with study procedures. The protocol was approved by the Institutional Review Board at each site (Fred Hutchinson Cancer Research Center, University of Minnesota, Dana-Farber Cancer Institute, Vanderbilt University, H. Lee Moffitt Cancer Center, Roswell Park Cancer Institute, Cleveland Clinic Foundation, University of British Columbia, M.D. Anderson Cancer Center and Duke University), and all patients on the study provided informed consent in accordance with the Declaration of Helsinki.

This analysis includes data from 190 patients who completed a cross-sectional survey collecting information regarding financial concerns, household income, employment status, insurance and out-of-pocket expenses. The survey was completed between June 2016 and July 2017 by the enrolled participants at the time of their standard clinic assessment and by some patients as a mailed-in survey because they had already completed their study-related visits on the parent study.

Financial Burden Survey

Multiple instruments have been developed to measure financial burden; however, none of them has yet been validated in the HCT population [14–16]. For this reason, we developed a 15-item survey (available in the Appendix) to collect information on financial concerns, household income, employment status, insurance and out-of-pocket expenses based on literature review and discussion with investigators on this study. Feedback regarding the content and face validity of the survey, ability of the respondent to interpret essential information, and the time required to read, comprehend, and complete it was collected from a small group of transplantation physicians and by piloting it with 3 patients with chronic GVHD at Mayo Clinic Arizona.

Study Variables

At enrollment, 3 months, 6 months, and 18 months, physicians and patients report standardized information on chronic GVHD organ involvement and symptoms. Chronic GVHD severity according to the National Institutes of Health chronic GVHD consensus criteria was scored using objective criteria for each organ, which were summed to give an overall score of mild, moderate, or severe. Standardized questions were given to patients to assess sociodemographic information at the time of study enrollment. Patients recorded their approximate annual family income in the year before transplantation as <$15,000, $15,000 to $24,999, $25,000 to $49,999, $50,000 to $74,999, $75,000 to $99,999, or ≥$100,000. These values were categorized into 3 groups for analysis: <$25,000 (low), $25,000 to $74,999 (medium), and ≥$75,000 (high). The highest grade of education was analyzed as high school or less (grade school, some high school, or high school graduate), some college, college graduate, or postgraduate degree. Current work status was analyzed as the ability to work or attend school (in school full time, in school part time, working full time, working part time, unemployed/looking for work), at home (homemaker, retired), or inability to work or attend school (on medical leave from work, disabled/unable to work, unemployed). Some variables, such as income and work status, were reported both at the time of enrollment and at the time of the financial survey.

Patient-Reported Outcomes

Physical and mental functioning

The Short Form Health Survey 36 (SF-36) is a validated 36-item self-report questionnaire that measures patient-reported health and functioning. The SF-36 Physical Component Score and Mental Component Score are 2 summary scales [17]. The scoring on this survey is norm-based, with a general population mean score of 50 and a standard deviation of 10. Higher scores indicate better functional status. The Human Activity Profile (HAP) consists of 94 questions designed to measure activity level. Three scores can be obtained from the HAP: maximum activity score, adjusted activity score, and modified adjusted activity score (mAAS). Only mAAS was included in our analysis, because it excludes activities that are restricted after HCT. Higher scores represent greater physical activity.

Depression/anxiety/difficulty sleeping

Three validated items from the Lee Chronic GVHD Symptom Scale were used to assess self-reported psychological symptoms [18]. Specifically, patients reported how much they have been bothered by depression, anxiety, or difficulty sleeping in the previous month using a 5-point scale (ranging from “not at all” to “extremely”). Summary scores were then calculated with a range of 0 to 100, with higher scores indicating greater difficulty.

Financial burden

Respondents were asked to report out-of-pocket medical expenses (eg, prescriptions, copayments, deductibles) and nonmedical expenses (eg, transportation to the clinic [eg, gas, parking], child care) over the previous 3 months. Financial burden was defined as the following: difficulty paying medical bills, not having enough money at the end of the month, reducing spending on home/leisure activities, needing assistance for gas/electric bills from utility companies, using retirement savings, borrowing money or selling assets (eg, house, car), or declaring bankruptcy. This was a dichotomous outcome and was operationally defined by the patient reporting at least 1 of the foregoing since being diagnosed with chronic GVHD. Perceived reasons for financial challenges were offered for endorsement: losing/changing insurance, inability of self/caregiver to return to work/having to return to a job with lower salary, frequent physician visits, and the need for multiple medications/treatment requirements. Resources used to help with financial difficulties, such as assistance from family/ friends/ fundraisers, help from charitable or nonprofit organizations, and resources suggested by social workers at transplantation centers, were also assessed.

Ability to work/attend School

Patients were considered able to return to work/school if they reported being in school or at work part time or full time at the time of survey irrespective of the work status at the time of enrollment.

Statistical Analysis

Differences between respondents and nonrespondents and between those who completed the survey in clinic versus by mail were determined using the chi-square test, Fisher exact test, *t* test, and Wilcoxon rank-sum test. The chi-square and *t* tests were used to compare the sociodemographic and clinical characteristics between respondents who reported a financial burden and those who did not. A stepwise regression analysis was used to select significant variables for building multivariate models for financial burden, using a *P* value threshold of <.1. The first model considered only baseline factors: age as a continuous variable, sex, race, education level, disease risk, graft source, and conditioning intensity. A second enhanced model examined chronic GVHD severity at baseline, HCT comorbidity index, physical and mental functioning (measured by SF-36), and activity level (measured by modified adjusted activity score) closest to survey completion and time from HCT added to the baseline model for their association with financial burden. Because of the collinearity between income and employment with financial burden, we did not include these 2 variables in the multivariate model but only reported their correlation with it. Assessment of factors associated with the ability to return to work/school was analyzed similarly.

RESULTS

Baseline Characteristics

A total of 383 patients were enrolled on the original Chronic GVHD Consortium protocol, out of which 281 were eligible to be surveyed and 190 responded, for a response rate of 68% (Figure 1). Demographic data and disease-related characteristics of the respondents (in-clinic versus mail survey) versus nonrespondents are presented in Table 1. There were no significant differences between nonrespondents and

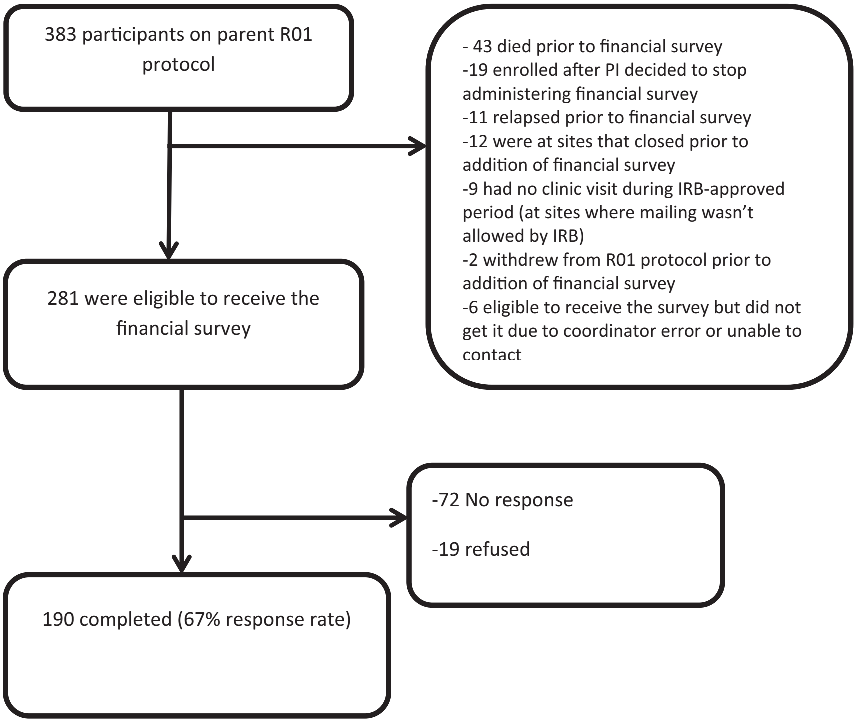

Figure 1. Response flowchart.

respondents, except that a higher proportion of nonrespondents had low income before HCT and less than a college degree. Disease distribution and conditioning intensity differed between the respondents who completed the survey in the clinic and those who completed it by mail. Moreover, the respondents who completed the survey by mail were further out from HCT compared with those who completed it in the clinic, as expected because mail was used for patients who had completed their study visits. The median patient age was 56 years (range, 12 to 79 years), and 87% of the patients were white. The median time from HCT to the onset of chronic GVHD was 7.5 months, and the median time from HCT to completion of the financial survey was 2.3 years. Physician-reported chronic GVHD severity was mild in 22% respondents, moderate in 53%, and severe in 22%. The median SF-36 Physical Component and Mental Component Scores closest to survey completion (median time, 21 days between the survey and SF-36) were 40.3 (range, 9 to 58) and 50.7 (range, 9 to 70), respectively.

Income/Education and Work Status

Seventy-three percent of patients had a graduate or higher degree. The proportion of patients reporting an annual household income $<\$25{,}000$ increased from 10% at enrollment to 20% at the time of survey completion. There was no significant change in the proportion of patients able to return to work/school from enrollment to the time of survey (33% versus 38%; $P = .36$). Working or being in school at the time of enrollment was associated with working/being in school at the time of the survey; 88% of those working at enrollment were currently working or in school, with only 12% currently not working or in school; $P < .001$). Twenty-seven percent of respondents reported being disabled/unable to work at the time of the survey. Table 2 presents selected comments of respondents in response to the question “Did your work status change since transplant?” Not surprisingly, working or being in school part time/full time at the time of the survey was associated with a higher income category (annual income $\geq\$50{,}000$ in 81% of those working/in school versus 47% of those not working/in school). Respondents who were working or in school also had higher physical and mental functioning as well as higher activity levels compared with those not working or in school ($P = .002$).

Out-of-Pocket Costs and Insurance Issues

Twenty-three percent and 39% of patients reported spending $>\$500$ in the last 3 months on healthcare-related nonmedical (eg, transportation to the clinic [gas, parking), child-care) and medical (eg, prescriptions, copayments, deductibles) out-of-pocket costs, respectively. All patients but 1 had health insurance at the time of the survey (51% private, 36% Medicaid/Medicare, and 13% other). One-third (34%) had faced insurance difficulties, such as delayed/denied coverage for specific treatments for chronic GVHD (65% for medications and 38% for laboratory tests/procedures, such as extracorporeal photopheresis), and this experience was correlated with a reported financial burden ($P = .05$).

Financial Burden, Reported Causes, and Sources of Assistance

Sixty-six percent of the respondents reported a financial burden; 24% had difficulty paying medical bills, 28% reported not having enough money at the end of the month, 49% reduced spending on utilities and other expenses, 31% used retirement savings, and 16% borrowed money or sold assets. The rate of bankruptcy was $<1\%$. Determinants of financial burden included the need for multiple medications/treatments (41%), inability to return to work (40%), frequent physician visits (32%), and losing/changing insurance (8%). Approximately one-half of the patients at >1 year out from HCT had made ≥ 4 visits to their transplantation center clinic (46%) or their hematologist (51%) in the previous 6 months. Assistance from family/friends or fund-raisers was a source for help with finances

Table 1
Baseline Characteristics by Financial Survey Response

Characteristic	Respondents (n = 190)		Nonrespondents (n = 91)	*P* Value[*]	
	In-Clinic (n = 110)	Mailed (n = 80)		Respondents versus Nonrespondents	In-Clinic versus Mailed
Age at enrollment, yr, median (IQR)	55 (39-63)	59 (46-65)	53 (38-62)	.13	.06
Male sex, n (%)	72 (66)	52 (65)	62 (68)	.63	.95
Race, n (%)				.18	.17
White	93 (85)	73 (91)	74 (81)		
Other	17 (15)	7 (9)	17 (19)		
Disease diagnosis, n (%)				.08	.02
Acute leukemia	49 (45)	43 (54)	36 (40)		
CML/MDS/MPD	37 (34)	12 (15)	18 (20)		
Lymphoma, including CLL	19 (17)	17 (21)	25 (28)		
Aplastic anemia/other	5 (4)	8 (11)	12 (13)		
Disease status, n (%)				.56	.61
Early	50 (45)	40 (50)	41 (45)		
Intermediate	39 (36)	29 (36)	38 (42)		
Advanced	21 (19)	11 (14)	12 (13)		
Stem cell source, n (%)				.06	.16
Bone marrow	11 (10)	3 (4)	2 (2)		
Cord blood	4 (4)	1 (1)	0		
Peripheral blood	94 (85)	76 (95)	89 (99)		
Missing	1 (1)	0	0		
Conditioning, n (%)				.70	.01
Myeloablative	64 (58)	30 (38)	47 (51)		
Reduced intensity	22 (20)	28 (35)	26 (29)		
Nonmyeloablative	24 (22)	22 (28)	18 (20)		
Chronic GVHD severity, n (%)				.07	.45
None	0	0	1 (1)		
Mild	24(23)	20 (26)	13 (14)		
Moderate	62 (58)	38 (49)	50 (55)		
Severe	20 (19)	19 (25)	27 (30)		
Annual income pre-HCT, $, n (%)				.03	.44
<25,000	12 (13)	6 (9)	6 (12)		
25,000-74,999	31 (33)	18 (27)	26 (50)		
≥75,000	51 (54)	43 (64)	20 (38)		
Baseline employment status, n (%)				.19	.59
Disabled/unemployed	44 (44)	27 (36)	32 (53)		
Full/part time	31 (31)	25 (34)	13 (22)		
Homemaker/retired	25 (25)	22 (30)	15 (25)		
Education, n (%)				.03	.72
Any college or higher	80 (82)	58 (79)	41 (67)		
No college	18 (18)	15 (21)	20 (33)		
Time from HCT to enrollment, yr, median (IQR)	1.5 (.7-2.8)	1.7 (.8-3.8)	2.1 (1-3.3)	.08	.49
Time from HCT to survey completion, yr, median (IQR)	2.3 (1.3-3.8)	3.9 (2.6-5.3)			<.0001
SF-36 PCS at baseline,[2] mean (SD)[†]	40.0 (8.8)	39.3 (10.1)	37.1 (11.6)	.08	.63
SF-36 MCS at baseline,[2] mean (SD)[†]	47.8 (12.2)	48.7 (10.7)	46.7 (12.4)	.39	.63
Modified adjusted activity score, mean (SD)	72.7 (11.5)	71.6 (9.9)	71.3 (11.8)	.55	.50

IQR indicates interquartile range; CML, chronic myelogenous leukemia; MDS, myelodysplastic syndrome; MPD, myeloproliferative disease; CLL, chronic lymphocytic leukemia; SF36 PCS, Short Form-36 Physical Component Scale; SF36 MCS, Short Form-36 Mental Component Scale.

[*] Chi-square test or Fisher exact test for categorical outcomes, t test or Wilcoxon rank-sum test for continuous variables.

[†] 99 of 110 in-clinic, 74 of 80 mailed, 60 of 91 nonresponders.

for 32% of respondents, whereas resources suggested by transplantation social workers or charitable organizations were used by 10% of respondents. Table 2 presents selective comments from respondents regarding causes of and assistance with financial concerns.

Factors Associated with Financial Burden and Return to Work/School

Table 3 describes the differences in sociodemographic and clinical characteristics between the respondents who had a financial burden and those who did not. In this univariate analysis, younger age, lower income, disability/unemployment, lower physical and mental functioning, lower activity level, and receipt of Medicare/Medicaid were associated with an increased risk of financial burden. In addition, psychological burdens, such as depression/anxiety and difficulty sleeping, were higher in those that reported a financial burden compared with those who did not (mean score, 26 versus 16; *P* = .004 in those with and without financial burden).

Race (white versus others: odds ratio [OR], .30; 95% confidence interval [CI], .07 to .92; *P* = .06) and age at enrollment (OR, .97; 95% CI, .95 to .99; *P* = .03) emerged as significant predictors of financial burden in the baseline multivariate model. In the enhanced model for financial burden, race (OR, .25; 95% CI, .06 to .78; *P* = .03), SF-36 MCS (OR, .97; 95% CI, .93 to 1.0; *P* = .03), and mAAS (OR, .97; 95% CI, .95 to 1.0; *P* = .05) were significant. Age lost its significance in the enhanced model.

In the stepwise regression analysis of ability to return to work/school at the time of the survey, age again emerged as a significant predictor in the baseline model (OR, .97; 95% CI, .95 to .99; *P* = .009) and remained significant in the enhanced model (OR, .97; 95% CI, .94 to .99; *P* = .005). Early risk disease was associated with a greater likelihood of returning to work/school in the baseline model (OR, 2.73; 95% CI, 1.1 to 7.3; *P* = .03) but lost its significance in the enhanced model where

Table 2
Narrative Comments from Patients about Financial and Employment Issues

Change in work status
Unable to work due to neuropathy, fatigue, multiple doctor visits, treatment every day; chronic GVHD restricted movement.
I went from full-time to retired on disability once cancer treatment started. Now post-transplant almost 5 years I am unable to work full-time due to fatigue and immune suppression.
Became disabled; too much missed work due to doctor appointments every 2 weeks and if I had a fever, being in the hospital for 6 days at a time.
Unable to work; too many negative side effects from medications and hospitalizations and appointments, Unpredictable complications keep arising.
I now work part-time, maybe 30 hours a week vs 50 hours/week before the transplant. Reduction due to less physical energy and less mental agility.
I was terminated from my position of president/CEO, now working part time for the same company in a lower capacity at 1/4 the pay.
Being a health care professional not able to work due to immunosuppression/steroid use and chronic GVHD.
I intended to return to the kind of work I've done before but can't because of GVHD related eye problems.
Causes and assistance for financial burden
Reduction in pay due to having to move to a part-time status
Divorce and loss of stable housing, rent is a huge challenge
Short sale of house; liquidating assets including retirement; living off disability
Selling everything that I owned that had any value, cashed out IRA
Savings are diminished drastically, but I manage
Retirement savings, sold automobile
Get food from food banks

mental functioning (SF-36 MCS) (OR, 1.06; 95% CI, 1.03 to 1.10; $P < .001$) and time from transplantation to the survey (OR, .82; 95% CI, .69 to .94; $P = .01$) emerged as significant.

DISCUSSION

Financial, insurance, and employment implications of allogeneic HCT have been reported [5–8,19]. In this multicenter cohort of patients with chronic GVHD, financial burden was reported by two-thirds of the respondents despite having health insurance. The need for multiple medications/ongoing treatment and inability to return to work were the major reasons for a financial burden, consistent with ongoing treatment for chronic GVHD. One-third of the respondents reported health insurance difficulties, with delays or denials of coverage, which is not surprising owing to the scarcity of Food and Drug Administration-approved treatments and no clearly defined pathways for treatment, but is of concern because patients with chronic GVHD have ongoing active medical issues. One-fourth of the respondents were unable to go back to work due to being disabled. Income decline was reported even from the time of enrollment to the present. The interplay of socioeconomic factors leading to financial hardships as has been reported in cancer survivors was also seen in our study [20,21]. Younger age was associated with a higher likelihood of financial burden in our baseline model (although not in the enhanced model), as it has been reported in other studies in the area, likely owing to the financial responsibilities of a younger household, inadequate time to build on savings, and lack of universal coverage, such as with Medicare [22,23]. Nonwhite race, lower SF36-MCS, and worse functional status also have been reported to be significantly associated with greater financial burden [22,24,25]. Out-of-pocket expenditures, in part from prescription copayments, known to be an important source of financial burden, remained high for this population even a long time out post-HCT [26,27]. Finally, we observed increased rates of depression and anxiety in those with financial burden, as has been described previously [8,24].

Our study clearly indicates that the prevention and amelioration of socioeconomic problems should be an adjunct to the care of patients with chronic GVHD, because improving overall patient well-being is a vital tenet of patient-centered care. It is important that chronic GVHD providers be able to recognize which patients and caregivers are at risk for adverse effects from financial burden to offer them timely assistance and support. A point to be noted is that this is a large cohort of patients with chronic GVHD across different transplantation centers in the United States and Canada who have steady health insurance, are receiving ongoing optimal post-HCT medical care, and have a reasonable functional status despite reporting substantial socioeconomic impacts of the disease. The situation is likely to be worse for patients who are extremely disabled, who lose their insurance, or who are forced to switch to plans with high deductibles, causing them to forego optimal care or to consider transplantation. Unfortunately, capturing this population might not always be possible because of fragmented post-HCT care and the lack of adequate longitudinal follow-up at most centers. Although the transplantation centers have a reasonably strong infrastructure that helps assess benefits and provides support to patients during HCT, this support is not quite as robust for post-HCT care.

Deleterious effects of financial burden, specifically high out-of-pocket costs worsening adherence to treatment and clinical outcomes have been reported by other investigators [28–31]. Patients with chronic GVHD are a medically vulnerable population, and the potential for noncompliance with care owing to financial hardship may lead to worse biomedical outcomes. Future research should investigate the use of tailored resources, such as structured rehabilitation programs, vocational assistance, interventions to increase employment rights awareness, financial planning, and assistance programs to ameliorate adverse financial and work-related implications for these patients. Although some of these strategies could be implemented by a multidisciplinary team at the transplantation center, others may require active engagement of referring/treating physicians, employers, payers, and nonprofit health care organizations/societies. In addition, the need for additional policy changes at the level of various stakeholders such as the transplantation center, payers, and federal government to ensure provision of adequate and affordable post-HCT care cannot be overemphasized [28–31].

A cross-sectional design, low representation of minority populations, a heavily insured population subset, and a high proportion of respondents with a higher educational status are some of the limitations of our study. Lack of matched chronic GVHD-free controls makes it difficult to tease out the specific impact of this complication from the overall financial burden occurring as a result of HCT itself. It is possible that those who did not respond or declined to participate were sicker and had a more significant financial burden, as was suggested by the lower income and lower education levels of nonrespondents at the time they enrolled into the parent study. We also did not ask specifically about the details of denial/delay in coverage or about the details of insurance coverage that would have impacted the financial burden, such as deductibles, coverage gaps, lifetime caps, and out-of-network costs. Patients from Canada were included in the study even though they have a different health care insurance system because some of the other factors contributing to financial burden, such as inability to work and need for multiple visits to health care providers, may still be prevalent in this subset. No differences were observed in the results when Canadian patients were removed from the dataset (data not shown). Finally, even though we

Table 3
Differences in Clinical and Sociodemographic Characteristics Between Respondents Without and with Financial Burden (FB)

Characteristic	Without (n = 64)	With (n = 126)	*P* Value
Age at enrollment, yr, mean (SD)	56 (14.2)	51 (14)	.010
Race, n (%)			.03
White	61 (95)	105 (83)	
Others	3 (5)	5 (17)	
Male sex, n (%)	42 (66)	82 (65)	1.000
Annual Income before HCT, $, n (%)			.07
<25,000 (low)	2 (4)	16 (15)	
25,000-74,999 (medium)	18 (32)	31 (30)	
≥75,000 (high)	36 (64)	58 (55)	
Annual income at survey, $, n (%)			<.001
<25,000 (low)	3 (5)	34 (29)	
25,000-74,999 (medium)	20 (35)	51 (43)	
≥75,000 (high)	35 (60)	34(29)	
Education, n (%)			.900
Any college or higher	46 (79)	92 (81)	
No college	12 (21)	21 (19)	
Baseline employment status, n (%)			.001
Disabled/unemployed	13 (22)	58 (50)	
Full/part time	25 (42)	31 (27)	
Homemaker/retired	21 (36)	26 (23)	
Employment status at survey, n (%)			<.001
Disabled/unemployed	11 (17)	56 (44)	
Full/part time	31 (48)	39 (31)	
Homemaker/retired	22 (34)	31 (25)	
Insurance type, n (%)			.061
Medicare/Medicaid	17 (27)	50 (40)	
Private	40 (63)	55 (44)	
Other	7 (11)	19 (15)	
Transplant source, n (%)			.236
Bone marrow	4 (6)	10 (8)	
Cord blood	0 (0)	5 (4)	
Peripheral blood	60 (94)	110 (88)	
Disease diagnosis, n (%)			.73
Acute leukemia	29 (45)	63 (50)	
CML/MDS/MPD	16 (25)	33 (26)	
Lymphoma, including CLL	15 (23)	21 (17)	
Aplastic anemia/other	4 (6)	9 (7)	
Disease status, n (%)			.263
Advanced	7 (11)	25 (20)	
Early	34 (53)	56 (44)	
Intermediate	23 (36)	45 (36)	
Conditioning, n (%)			.262
Myeloablative	28 (44)	66 (52)	
Reduced intensity	16 (25)	34 (27)	
Nonmyeloablative	20 (31)	26 (21)	
SF-36 PCS closest to survey completion, mean (SD)	42.5 (9.6)	38.2 (8.9)	.004
SF-36 MCS closest to survey completion, mean (SD)	51.5 (9)	46.4 (12.3)	.006
Modified adjusted activity score closest to survey completion, mean (SD)	69.5 (13.3)	63.5 (13.9)	.007
Comorbidity index, baseline median (range)	2 (0-7)	2 (0-9)	.848
Chronic GVHD severity, n (%)			.431
Mild	17 (27)	27 (22)	
Moderate	35 (57)	65 (54)	
Severe	10 (16)	29 (24)	
Visit type, n (%)			.157
Clinic	32 (50)	78 (62)	
Mailed in	32 (50)	48 (38)	
Institution location, n (%)			.779
Canada	6 (9)	15 (12)	
United States	58 (91)	111 (88)	
Time from HCT to survey, yr, mean (SD)	3.6 (2.2)	3.5(2.6)	.610
Depression/anxiety/difficulty sleeping score, mean (SD)	15.7 (14.3)	25.6 (23.9)	.004

had a good response rate and reasonable sample size, our sample still may have been too small to detect significant associations in the multivariate analysis. Other studies have reported age, race, income level, sex, primary language, and work status as significant predictors of financial burden in other cancer populations.

Notwithstanding the limitations, this study is one of the first comprehensive reports on the sociomedical profile of patients with chronic GVHD. The adverse socioeconomic and psychosocial consequences of this devastating iatrogenic complication of HCT add on to the burden caused by medical complications associated with it. Efforts to decrease the incidence of chronic GVHD and to help those suffering from chronic GVHD to preserve their assets and minimize financial burden may significantly improve patients' quality of life after HCT.

ACKNOWLEDGMENTS

Financial disclosure: This study was funded by the National Cancer Institute (Grant CA118953).

Conflict of interest statement: There are no conflicts of interest to report.

SUPPLEMENTARY DATA

Supplementary data related to this article can be found online at doi:10.1016/j.bbmt.2018.09.040.

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