HHS Public Access

Author manuscript

Cancer. Author manuscript; available in PMC 2020 September 01.

Published in final edited form as:

Cancer. 2020 June 01; 126(11): 2679–2686. doi:10.1002/cncr.32808.

Prevalence of decisional regret among patients who underwent allogeneic hematopoietic stem cell transplantation and associations with quality of life and clinical outcomes

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Abstract

Background—Allogeneic hematopoietic cell transplantation (alloHCT) is a potentially curative but with known negative effects on quality of life. We investigated whether patients expressed regret after HCT and the relationships between clinical outcomes, and quality of life.

Methods—We used Center for International Blood and Marrow Transplant Research data from 184 adults who completed the Functional Assessment of Cancer Therapy-Bone Marrow Transplant (FACT-BMT) pre-alloHCT and at day 100. Additional timepoints were 6 and 12 months. Regret was measured with a FACT-BMT item not included in scoring, "I regret having the bone marrow transplant." We evaluated FACT-BMT scores and regret using t-tests. We used covariance pattern models to determine predictors of regret over time, including baseline characteristics and post-alloHCT outcomes (acute or chronic graft-versus-host-disease; disease relapse).

Results—At 100 days, 6 and 12 months, 6–8% of patients expressed regret; a total of 15% expressed regret at any timepoint. Regret was associated with lower FACT-BMT at 6 and 12 months ($p<0.001$). Higher baseline FACT-BMT and social well-being were associated with a reduced risk of expressing regret. The risk of regretting transplantation was 17.5 percentage points (CI 5.5–29.7) greater in patients that relapsed post-HCT, compared to patients who did not.

Conclusions—Among alloHCT patients who lived to 100 days, most did not report regretting their transplant. Regret was related to disease relapse. Social connectedness may serve as a protective factor against later regret. Future work should explore regret in other patient groups and use qualitative methods to inform best practices for reducing regret.

Concise Two Sentences on Conclusions

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Author Contributions: All authors (RC, HRT, AD, BES, KEF) were responsible for the design and execution of the study and wrote the manuscript. HRT ran analyses. All authors approved the final draft of the manuscript.

Conflict of Interest statement: The authors declare that they have no conflicts of interest.

Among patients who underwent allogenic HCT and lived to at least 100 days, most did not report regretting their transplant, though 15% did within 1 year. Relapse significantly increased the risk of reporting regret while baseline social well-being significantly decreased the risk of regret.

Keywords

allogeneic hematopoietic stem cell transplantation; regret; FACT-BMT; longitudinal

Introduction

More than 45,000 people receive hematopoietic stem cell transplantation (HCT) annually throughout the world.[1] In the United States in 2015, almost 14,000 autologous HCTs and 8,000 allogeneic transplants were performed, numbers that have been consistently increasing since the early 2000s.[2] HCT is a physically and psychologically demanding treatment approach, with known implications on mood, depression, and sleep among transplant recipients.[3–5] One study indicated a substantial percentage of patients (43.3%; N = 90) expressed clinically significant symptoms of depression 6 months post-transplant and suggested lower quality of life and higher depression during hospitalization were strong predictors of lower quality of life at 6 months.[6] Declining quality of life, specifically physical and social quality of life, 100 days post-transplant compared to pre-transplant quality of life has been demonstrated in Swedish[7] and U.S. populations.[8] These studies suggest time after transplant, both in and out of the hospital, are related to quality of life and well-being. Importantly, quality of life has demonstrated a parabolic relationship with time, beginning at baseline, declining after transplant, and returning to baseline levels at one year.[9]

Decisional regret is a negative emotion involving distress or remorse following a healthcare decision and has been associated with lower satisfaction with medical decision making and lower quality of life.[10, 11] A systematic review of decisional regret in medical decisions highlights eight risk factors, including the decision-making process, treatment-related complications, and quality of life.[10] However, none of the 56 studies reviewed in this study pertained to HCT patients (though 66% were in oncology settings). Another review of research on regret in cancer-related decisions identified several studies where patients reported substantial regret in relation to decisions, specifically men's regret about treatment for early prostate cancer[12] and women's regret regarding bilateral mastectomy.[13, 14] Collectively, previous reviews demonstrate post-decisional regret, particularly among cancer-related decisions, occurs for some patients.

Little is known about decisional regret among HCT patients, with even less known about regret over time post-HCT or in the context of severe HCT side effects such as chronic graft versus host disease (cGVHD) or disease relapse. In one post-transplant study, 14 of 406 (3%) adult HCT survivors 12 to 36 months after their transplant (60% autologous transplant, 30% allogeneic) expressed regret about having their bone marrow transplant.[15] Focus groups with allogeneic transplant (alloHCT) survivors suggest some survivors regret their transplant or would not go through with a transplant in hindsight because of the side effects and burden on caregivers.[16]

A commonly used health-related quality of life measure in HCT is the Functional Assessment of Cancer Therapy-Bone Marrow Transplant (FACT-BMT),[9] which includes a single item measuring regret. The FACT-BMT measures five dimensions of quality of life with corresponding subscale scores; however, the single regret item is not included in scoring.[17] Therefore, much of the literature does not report on results from this item, limiting our understanding of the degree to which HCT patients experience decisional regret about their transplant.

We sought to understand whether regret about HCT was correlated with pre-HCT attributes or post-HCT outcomes, specifically acute graft-versus-host-disease (aGVHD), chronic graft-versus-host-disease (cGVHD), or relapse. Second, we investigated whether regret about HCT was associated with time elapsed from transplant.

Materials and Methods

Patients

This was a secondary analysis of data from the Center for International Blood and Marrow Transplant Research (CIBMTR) database. The CIBMTR prospectively enrolled 390 patients from seven transplant centers between 2011 to 2013 to assess the feasibility of centralized collection of patient-reported outcomes.[18] Of those enrolled, 264 adult patients returned the baseline FACT-BMT survey. Of the adult patients included in the pilot study, 11 patients who received HCT for a non-malignant disease were excluded. Patients were also excluded if their baseline FACT-BMT survey was not scorable (<50% complete) (n=1) or they did not answer the main outcome question on regret at any time point (n=68). Thus, a total of 184 patients were considered for analyses of baseline predictors of regret. We examined whether there were differences in patient characteristics between included patients and those who were excluded because they did not respond to the regret item at any subsequent timepoint.

Covariates

Patients' health-related quality of life was assessed using the FACT-BMT and its subscales. Adult patients completed the FACT-BMT[17] at four timepoints: before HCT, at day 100, at 6 months, and 1-year post transplant. The FACT-BMT includes multiple scored subscales: physical well-being (PWB), 7 items; social well-being (SWB), 7 items; emotional well-being (EWB), 5 items; functional well-being (FWB), 7 items; bone marrow transplant subscale (BMTS), 10 items; trial outcome index (TOI = PWB +FWB+BMTS), 24 items; and FACT general (FACT-G=PWB+SWB+EWB+FWB+RWD [relationship with doctors, 2 items]), 28 items. Higher scores indicate better functioning.

Sociodemographic characteristics were assessed at baseline and included age, sex, race, marital status, education level, and income.

Clinical characteristics were also assessed at baseline. Primary indication for HCT included acute leukemia, chronic myeloid leukemia (CML), myelodysplastic/myeloproliferate neoplasm (MDS/MPN), other leukemia, Non-Hodgkin lymphoma (NHL), Hodgkin's lymphoma (HL), and plasma cell disorders/multiple myeloma. Karnofsky performance score was recorded and dichotomized to indicate those patients below 90 and those at or above 90.

Relapse, cGVHD, and aGVHD are clinical data reported by the transplant centers and assessed at 100 days post-HCT, 6 months, and 12-months post-HCT. These clinical outcomes were tested as independent variables predicting regret.

Outcome Measures

The FACT-BMT "Additional Concerns" section includes two questions that are not scored, one of which states, based on the past 7 days, "I regret having the bone marrow transplant," with response options 0=not at all, 1=a little bit, 2=somewhat, 3=quite a bit, 4=very much. These categories were dichotomized into expressing any regret (1=a little bit, 2=somewhat, 3=quite a bit, 4=very much = 1 any regret) and expressing no regret (0 not at all = 0 no regret).

Statistical Analysis

Patient characteristics were summarized using descriptive statistics. Frequencies and percentages were used for categorical covariates, while median and range were used for continuous covariates. Number of patients alive at each time point and their responses to the binary regret outcome were also described. We used box plots to show the relationship between FACT-BMT scores and regret at each timepoint and T-tests to evaluate differences in mean scores. These statistical analyses were performed using RStudio version 1.1.456 (RStudio Inc).

Covariance pattern modeling was used to determine baseline predictors of regret over time. Independent, compound symmetry, first-order autoregressive, Toeplitz, and unstructured covariance structures were investigated as potential covariance structures for the data and first-order autoregressive was chosen based on Akaike and Bayesian information criteria (AIC and BIC).[19, 20] Unadjusted analyses assessed the impact of each individual covariate on regret over time and significant covariates were considered in a multivariable model. Interactions between covariates and between covariates and time were examined.

Similar analyses were conducted to investigate the relationships among post-HCT regret and aGVHD, cGVHD, and relapse. Acute GVHD was measured as a dichotomous variable indicating whether or not a patient experienced aGVHD by day 100. Chronic GVHD and relapse were tested as time-dependent covariates in predicting regret over the time points of 100 days, 6 months, and 12 months post-HCT. Relapse and cGVHD were considered a "yes" if diagnosed at any time prior to the time point and remained a "yes" for any subsequent time point. Two-sided alpha value of 0.05 was used throughout all analyses. These statistical analyses were completed using Stata version 15.1.

Results

Comparing included and excluded patients

The 184 patients included in the study were compared to the 68 patients who were not included because of incomplete regret questions or death before 100 days (Supplemental Table A). The two groups were similar on many characteristics, including age, sex, educational level, Karnofsky performance score, and conditioning regimen intensity.

Compared to those excluded, included patients were more often white, married, with a higher household income, and/or reported higher FACT-BMT scores at baseline. Further, these two groups also differed on some clinical characteristics, including HCT-CI and graft source, with a larger portion of those patients excluded from the analysis receiving cord blood for graft source.

Patient Characteristics

Sociodemographic and clinical baseline characteristics of the 184 included patients can be found in Table 1. Eighty-four percent of patients were alive at 12-months post-HCT. Table 2 describes clinical outcomes, including survival, relapse, cGVHD, and aGVHD by timepoint. The prevalence of aGVHD at 100 days was 36%, 1% had cGVHD, and 7% of patients had relapsed disease. Those percentages increased at subsequent timepoints with cumulative incidences of 43% (95% Confidence Interval [CI] 36–51%) experiencing cGVHD and 17% (95% CI 12–24%) experiencing relapse by 12 months.

Regret Over Time

Twenty-eight (15%) unique patients reported regret post-HCT at any time point (Table 3). At each time point, regret was reported by 6–8% of the living patients, with missing responses for 11–17%.

Figure 1 shows box plots of average FACT-BMT score reported at each time point, stratified by those who expressed regret and those who do not. Among those who did not report regret, the average FACT-BMT score increased slightly at each timepoint (100 days = 101; 6 months = 106; 12 months = 109). However, for those who expressed regret, the trend was in the opposite direction and with a larger magnitude of change (100 days = 94; 6 months = 79; 12 months = 77). At each timepoint the average FACT-BMT score was higher for those who did not express regret compared to those who expressed regret. At 6 months and 12 months, the difference was statistically significant ($p<.001$).

Covariance Patterns of Baseline Characteristics with Regret Overtime

Unadjusted covariance pattern models for baseline variables (Table 4) showed that baseline FACT subscales SWB ($p=0.014$), BMTS ($p=0.013$), TOI ($p=0.037$), FACT-G ($p=0.021$) as well as the total FACT-BMT score ($p=0.012$) were all significantly and negatively associated with regret over time. Higher baseline SWB, BMTS, TOI, FACT-G and FACT-BMT significantly reduced the risk of expressing regret at subsequent timepoints. Patients' HCT-CI was positively and significantly associated with regret over time. Baseline variables that were not significant include: age, sex, race, marital status, education level, income, primary disease, Karnofsky performance score, conditioning regimen intensity, donor, graft source, and year of transplant.

Unadjusted models showed post-HCT disease relapse was a significant risk factor for decisional regret ($p=0.004$), but post-HCT cGVHD was not ($p=0.88$) (Table 4). The risk of regretting transplantation was 17.5 percentage points greater (CI 5.5–29.7) in patients that relapsed post-HCT, compared to patients who did not relapse.

On multivariate analysis, only the baseline FACT-BMT score was significantly associated with post-HCT regret, therefore, results are not shown. No significant two-way interactions were found.

Discussion

To the best of our knowledge, this is the first study to assess the relationship between reporting regret after allogeneic HCT and patient and clinical outcome characteristics over time. We observed a consistent proportion of 6–8% of patients expressing regret at each follow-up time point (100 days, 6 months, and 12 months). This is higher than the previous cross-sectional study of patients reporting regret 12–36 months after their transplant, in which 3% of patients expressed regret, though we note that in that study, the researchers included those who answered "1=a little bit" in the category of not expressing regret.[15] While conceptually we think expressing any regret is meaningful, using this operationalization, our sample proportions would be 1% at 100 days, 5% at six months, and 2% at 12 months. Importantly, our patient population was entirely those who had undergone allogeneic transplantation, while the patient population in Mosher et al. included about 60% autologous transplants, which are associated with lower toxicity and no GVHD risk.

Our findings suggest a relationship between baseline social well-being and later reporting regret about transplant. Previous studies have demonstrated the frustrations among survivors regarding their social connectedness post-transplant, referencing feelings of guilt because of the impact on their significant others.[21] Our results suggest it may be those who begin with lower connectedness and social well-being that are more at risk for later regret, perhaps due to guilt for impacting a smaller social network. Public health and social science research cite social cohesion as a protective factor against poor health outcomes.[22–25] Our findings on baseline social well-being extend this literature to suggest increased social connectedness may serve as a protective factor against later regret in health decisions.

Considered a 'high-stakes' medical treatment, the decision-making process, and relatedly the informed consent process, for HCT is complex. Patients are often in a vulnerable state when asked to make decisions about treatment for a life-threatening illness that may have severe side effects.[26] A review of the literature suggests patients consenting for HCT often later do not recollect risks and complications explained in consent discussions and, overall, lack in engagement with the consent education process.[26, 27] This disconnect in patients' understanding and engagement in the consenting process may lead some patients, especially those who experience relapse, to later express regret about having a transplant.

Three types of decisional regret have been described: outcome regret where the focus of regret is the outcome (i.e. relapse), option regret where the focus of the regret is the decision chosen (i.e. consenting to transplant), and process regret where the focus is on the process leading to the decision (i.e. unsuccessful educational process, materials, and/or delivery).[14] Given our data, we were only able to formally evaluate the first type, and our findings do point to some patients experiencing outcome regret, as relapse was significantly associated with a higher risk of regret over time. Here, the intended outcome of a transplant (i.e. cure from disease) did not occur, but rather relapse occurred, which may have led to regret in

having the transplant. Further, Beccera et al. recognized risk factors for decisional regret in their systematic review, highlighting higher decisional conflict, serious adverse physical health outcomes, more treatment complications, more anxiety, and harm to body image as some of the more prominent risk factors.[10] Each of these risks can occur in HCT, making it important to understand how patients came to regret their transplants. Future qualitative research to ask patients why they express regret could help clarify whether some transplant patients have option regret or process regret, and which risk factors for regret occur among HCT patients.

Though little research has been done to address regret after HCT, some research points to opportunities in the educational process as a major opportunity to mitigate post-decision regret. It is known that educational materials and delivery methods should be objective and accurate since transplant patients tend to overestimate the benefits of BMT.[6, 28] Successful education has been associated with decreased distress and increased patient satisfaction,[28, 29] by better preparing patients for the transplant process. Though not formally assessed in the current literature, regret in transplant may likely stem from education that is not appropriately tailored to transplant patients' cultural background, barriers to learning, and preferential learning styles.[28, 30] Future research may employ qualitative methods to better understand which type of regret is more prevalent among transplant patient and whether the regret is rooted in dissatisfaction with education, with consenting to transplant, or something else. Additionally, individual centers could ask about regret through their exit surveys years after transplant, which may broaden our understanding of long-term regret.

Although this study is limited in its sample size and use of a single item to operationalize regret, this research provides the first longitudinal assessment of decision regret among post-HCT patients and can provide an initial benchmark for allogeneic transplant regret. Other important limitations to recognize, however, are the potential non-response bias, as patients included in this study had to survive to 100-days to complete the post-HCT regret item. Our comparison of included and excluded patients demonstrated that those excluded were significantly different on a number of sociodemographic and clinical characteristics, so it is important to remember that the perspectives of these individuals is underrepresented in our analysis. The excluded patients were significantly more likely to be racial/ethnic minorities, not married, with higher HCT-CI, and have lower FACT scores for emotional well-being, which are all previously identified risk factors for decisional regret.[10] Thus, this study may be underestimating the true incidence of regret after alloHCT. Future studies would benefit from including qualitative investigations into the specific type and source of regret of HCT patients, as well as focusing on patients that are underrepresented in current studies.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgements

The CIBMTR is supported by the National Institutes of Health (NIH) grants Nos. U24CA076518 and HL069294 Health Resources and Service Administration (HRSA) contract No. HHSH250201200016C. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the NIH.

Heather Tecca was supported in part by the Midwest Center for Occupational Safety and Health training grant CDC/NIOSH 2T42 OH008434.

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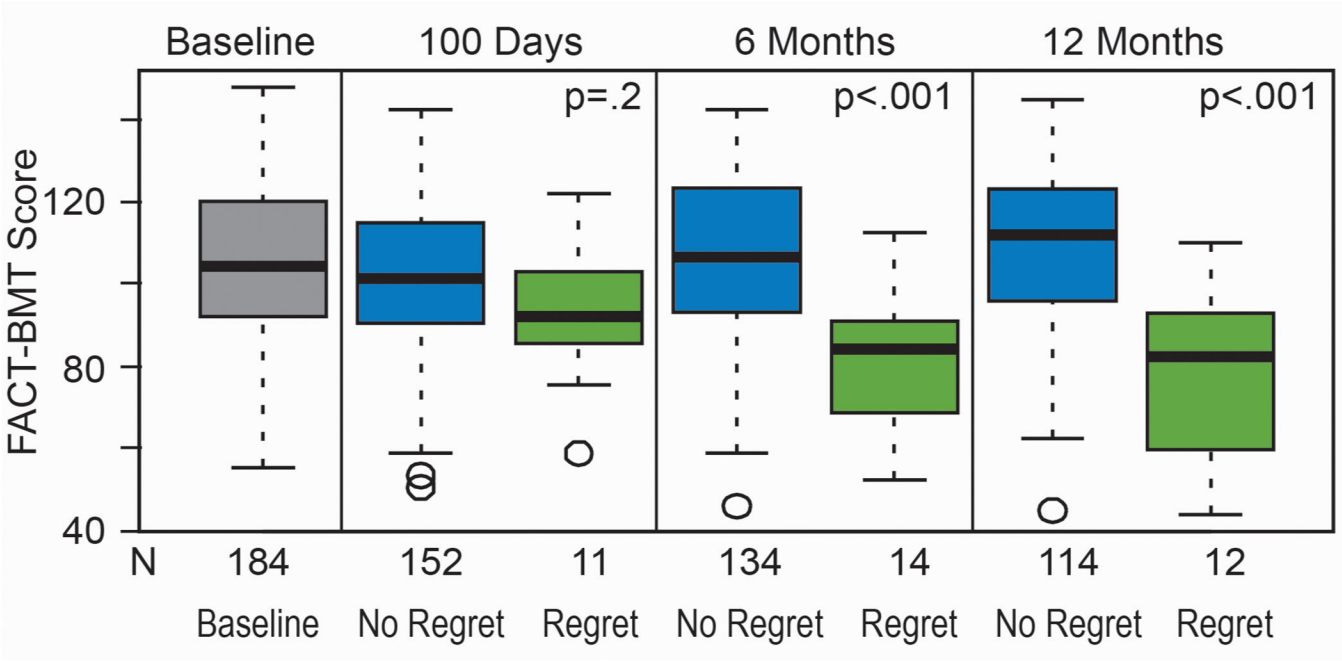

Figure 1.

Box plots of Functional Assessment of Cancer Therapy–Bone Marrow Transplant (FACT-BMT) scores at baseline, 100 days, 6 months, and 12 months stratified by those patients who expressed regret and those patients who did not

Table 1.

Patient Characteristics (n=184)

Variable	N (%)
Median age at transplant (range), years	54 (21–75)
18–29	15 (8)
30–39	18 (10)
40–49	27 (14)
50–59	62 (34)
60–69	57 (31)
70+	5 (3)
Sex	
Male	107 (58)
Female	77 (42)
Race	
White	172 (94)
Non-white	10 (5)
Unknown	2 (1)
Marital status	
Married or living with partner	139 (75)
Single/separated/divorced/widowed	31 (17)
Unknown	14 (8)
Education	
Secondary education or less	38 (21)
Vocational/associates degree	49 (27)
Bachelors/graduate degree	89 (48)
Unknown	8 (4)
Income	
< $60,000	31 (17)
≥ $60,000	63 (34)
Unknown	90 (49)
Primary indication for HCT	
Acute leukemia	95 (52)
CML	12 (6)
MDS/MPN	38 (21)
Other leukemia	15 (8)
NHL	16 (9)
HL	4 (2)
Plasma cell disorders/multiple myeloma	4 (2)
Karnofsky performance score	
≥ 90	115 (63)
< 90	69 (37)
Median baseline FACT-BMT score (range)	104 (55–148)

Variable	N (%)
Baseline PWB subscore	23 (5–28)
Baseline SWB subscore	21 (10–28)
Baseline EWB subscore	19 (6–24)
Baseline FWB subscore	18 (4–28)
Baseline BMT subscore	28 (10–40)
Baseline TOI subscore	67 (25–96)
Baseline FACTG subscore	79 (45–108)
Median HCT-CI (range)	2 (0–8)
0	52 (28)
1	31 (17)
2	30 (16)
3	37 (20)
4	13 (7)
≥5	16 (9)
Unknown	5(3)
Conditioning regimen Intensity	
Myeloablative	99 (54)
RIC/NMA	85 (46)
Donor	
Unrelated	101 (55)
Related	83 (45)
Graft source	
Bone marrow	22 (12)
Peripheral blood	151 (82)
Cord blood	11 (6)
Year of transplant	
2011	14 (8)
2012	133 (72)
2013	37 (20)
Median clinical follow up (range), months	24 (5–38)

CML = Chronic Myelogenous Leukemia; MDS/MPN = Myelodysplastic/Myeloproliferative Neoplasms; NHL = Non-Hodgkin Lymphoma; HL = Hodgkin Lymphoma; PWB = physical well-being; SWB = social well-being; EWB = emotional well-being; FWB = functional well-being; TOI = trial outcome index; FACT-G = FACT general; HCT-CI = Hematopoietic Cell Transplant Co-morbidity Index; RIC/NMA = reduced-intensity conditioning/non-myeloablative

Table 2.

Number and Percentage of Patients Experiencing Clinical Outcomes by time Point

	Survival	Relapse	cGVHD
Events occurred before 100 days	-	12 (7%)	2 (1%)
N for cumulative incidence analysis	184	172	182
6 months	95.7 (92.2–98.1)%	7.6 (4.1–12)%	17.5 (12.1–23.6)%
12 months	83.7 (78–88.7)%	17.4 (12.1–23.5)%	43.4 (35.9–51)%

Note: Surviving 100 days is part of the inclusion criteria

Table 3.

Description of regret responses by time point

	100 days	6 months	12 months
Alive at time point	184	172	152
Regret	11 (6%)	14 (8%)	12 (8%)
A little bit (1)	9	6	9
Somewhat (2)	2	6	2
Quite a bit (3)	-	2	1
No regret	152 (83%)	134 (78%)	114 (75%)
Withdrew	0	0	1 (1%)
No response to regret question	0	3 (2%)	2 (1%)
Did not complete questionnaire	21 (11%)	21 (12%)	23 (15%)

Table 4.

Unadjusted covariance pattern modeling associations between baseline covariates and regret over time

Variable	Coefficient (95% CI)	P-value
Age	−0.002 (−0.005, 0.001)	0.106
Female sex	−0.044 (−0.113, 0.026)	0.219
Non-white race	−0.015 (−0.178, 0.149)	0.859
Married or living with partner	−0.075 (−0.171, 0.021)	0.127
Education		
Secondary education or less	REF	0.875
Associate's or vocational degree	−0.013 (−0.116, 0.090)	0.798
Bachelor's degree or higher	0.047 (−0.084, 0.101)	0.853
Income ≥ $60,000	−0.007 (−0.080, 0.067)	0.858
Primary indication for HCT		
Acute leukemia	REF	0.831
CML	−0.014 (−0.152, 0.124)	0.846
MDS/MPN	−0.013 (−0.103, 0.078)	0.781
Other leukemia	0.013 (−0.114, 0.139)	0.845
NHL	−0.059 (−0.183, 0.064)	0.345
HL	0.112 (−0.118, 0.341)	0.340
Plasma cell malignancy/MM	−0.101 (−0.325, 0.123)	0.376
Karnofsky performance score ≥ 90	−0.042 (−0.114, 0.029)	0.248
Baseline FACT-BMT score	−0.002 (−0.004, −0.001)	0.012
Baseline PWB subscore	−0.007 (−0.014, 0.001)	0.083
Baseline SWB subscore	−0.011 (−0.020, −0.002)	0.014
Baseline EWB subscore	−0.008 (−0.017, 0.001)	0.055
Baseline FWB subscore	−0.003 (−0.010, 0.003)	0.282
Baseline BMT subscore	−0.008 (−0.013, −0.002)	0.013
Baseline TOI subscore	−0.003 (−0.005, −0.001)	0.037
Baseline FACTG subscore	−0.003 (−0.006, −0.001)	0.021
HCT-CI	0.026 (0.006, 0.046)	0.011
Myeloablative conditioning regimen	0.006 (−0.063, 0.076)	0.857
Related donor	−0.014 (−0.066, 0.039)	0.602

Variable	Coefficient (95% CI)	P-value
Graft source		
Bone marrow	REF	0.352
Peripheral blood	0.028 (−0.078, 0.135)	0.605
Cord blood	0.125 (−0.048, 0.298)	0.157
Year of transplant		
2011	REF	0.156
2012	0.090 (−0.042, 0.221)	0.180
2013	0.142 (−0.005, 0.288)	0.058
Post-HCT aGVHD within 100 days	0.048 (−0.033, 0.128)	0.247
Post-HCT relapse[+]	0.176 (0.055, 0.297)	0.004
Post-HCT cGVHD[+]	0.008 (−0.091, 0.106)	0.880

[+]These clinical outcomes are modeled as time varying

Note: Positive coefficient indicates increased risk of expressing regret over time; Negative coefficient indicates decreased risk of expressing regret over time