Original Article

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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BACKGROUND: Allogeneic hematopoietic stem cell transplantation (alloHCT) is potentially curative but with known negative effects on quality of life. In the current study, the authors investigated whether patients expressed regret after undergoing HCT and the relationships between clinical outcomes and quality of life. **METHODS:** 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) before undergoing alloHCT and at day 100 were used. Additional time points were 6 months and 12 months. Regret was measured using a FACT-BMT item not included in scoring: "I regret having the bone marrow transplant." The authors evaluated FACT-BMT scores and regret using Student *t*-tests. Covariance pattern models were used to determine predictors of regret over time, including baseline characteristics and post-alloHCT outcomes (acute or chronic graft-versus-host-disease, disease recurrence). **RESULTS:** At 100 days, 6 months, and 12 months, approximately 6% to 8% of patients expressed regret; a total of 15% expressed regret at any time point. Regret was found to be associated with lower FACT-BMT scores at 6 months and 12 months ($P < .001$). Higher baseline FACT-BMT and social well-being scores were associated with a reduced risk of expressing regret. The risk of regretting transplantation was 17.5 percentage points (95% confidence interval, 5.5-29.7 percentage points) greater in patients who developed disease recurrence after HCT compared with patients who did not. **CONCLUSIONS:** Among patients who underwent alloHCT and lived to 100 days, the majority did not report regretting their transplantation. Regret was found to be related to disease recurrence. 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. ***Cancer* 2020;126:2679-2686**. © *2020 American Cancer Society*.

KEYWORDS: allogeneic hematopoietic stem cell transplantation, Functional Assessment of Cancer Therapy–Bone Marrow Transplant (FACT-BMT), longitudinal, regret.

INTRODUCTION

Greater than 45,000 individuals undergo hematopoietic stem cell transplantation (HCT) annually throughout the world.[1] In the United States in 2015, nearly 14,000 autologous HCTs and 8000 allogeneic transplantations were performed, numbers that have been increasing consistently since the early 2000s.[2] HCT is a physically and psychologically demanding treatment approach, with known effects on mood, depression, and sleep among transplantation recipients.[3-5] One study indicated a substantial percentage of patients (43.3%; 90 patients) expressed clinically significant symptoms of depression 6 months after transplantation and suggested that lower quality of life and higher depression during hospitalization were strong predictors of a lower quality of life at 6 months.[6] Declining quality of life, specifically physical and social quality of life, 100 days after transplantation compared with pretransplantation quality of life has been demonstrated in Swedish[7] and US patient populations.[8] These studies have suggested that time after transplantation, both in and out of the hospital, is related to quality of life and well-being. It is important to note that quality of life has demonstrated a parabolic relationship with time, beginning at baseline, declining after transplantation, and returning to baseline levels at 1 year.[9]

Decisional regret is a negative emotion involving distress or remorse after a health care 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 has highlighted 8 risk factors, including the decision-making process, treatment-related complications, and quality of life.[10] However, to the best of our knowledge, none of the 56 studies reviewed in this study pertained to patients who underwent HCT, although 66% were in oncology settings. Another review of research regarding

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regret in cancer-related decision making identified several studies in which 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 have demonstrated that postdecisional regret, particularly among patients making cancer-related decisions, occurs for some patients.

To the best of our knowledge, little is known regarding decisional regret among patients undergoing HCT, with even less known regarding regret over time after HCT or within the context of severe HCT side effects such as chronic graft-versus-host disease (cGVHD) or disease recurrence. In 1 posttransplantation study, 14 of 406 adult HCT survivors (3%) who were 12 to 36 months after their transplantation (60% with autologous transplantation and 30% with allogeneic transplantation) expressed regret about undergoing their bone marrow transplantation.[15] Reports from focus groups with survivors of allogeneic HCT (alloHCT) have suggested that some survivors regret their transplantation or in hindsight would not go through with a transplantation 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 5 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, thereby limiting our understanding of the degree to which patients who undergo HCT experience decisional regret about their transplantation.

We sought to understand whether regret about HCT was correlated with pre-HCT attributes or post-HCT outcomes, specifically acute GVHD (aGVHD), cGVHD, or disease recurrence. Second, we investigated whether regret about HCT was associated with time elapsed from transplantation.

MATERIALS AND METHODS

Patients

The current study was a secondary analysis of data from the Center for International Blood and Marrow Transplant Research database. The Center for International Blood and Marrow Transplant Research prospectively enrolled 390 patients from 7 transplantation centers between 2011 and 2013 to assess the feasibility of the 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 underwent HCT for a nonmalignant disease were excluded. Patients also were excluded if their baseline FACT-BMT survey was not scorable (<50% complete) (1 patient) or they did not answer the main outcome question regarding regret at any time point (68 patients). Thus, a total of 184 patients were considered for analyses of the baseline predictors of regret. We examined whether there were differences with regard to patient characteristics between included patients and those who were excluded because they did not respond to the regret item at any subsequent time point.

Covariates

Patients' health-related quality of life was assessed using the FACT-BMT and its subscales. Adult patients completed the FACT-BMT[17] at 4 time points: 1) before HCT; 2) at day 100; 3) at 6 months; and 4) at 1 year after transplantation. 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 transplantation subscale (BMTS; 10 items); trial outcome index (TOI [PWB, FWB, and BMTS]; 24 items); and the FACT–General (FACT-G [PWB, SWB, EWB, FWB, and relationship with doctors; 2 items]; 28 items). Higher scores indicated better functioning.

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

Clinical characteristics also were assessed at baseline. Primary indications for HCT included acute leukemia, chronic myeloid leukemia, myelodysplastic syndrome/myeloproliferative neoplasm, other leukemia, non-Hodgkin lymphoma, Hodgkin lymphoma, and plasma cell disorders/multiple myeloma. The Karnofsky performance score was recorded and dichotomized to indicate those patients with a score <90 and those with a score ≥90.

Disease recurrence, cGVHD, and aGVHD are clinical data reported by the transplantation centers and assessed at 100 days after HCT and at 6 months and 12 months after HCT. These clinical outcomes were tested as independent variables predicting regret.

Outcome Measures

The FACT-BMT category addressing "Additional Concerns" includes 2 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 of 0 (indicating not at all), 1 (indicating a little bit), 2 (indicating somewhat), 3 (indicating quite a bit), and 4 (indicating very much). These categories were dichotomized into expressing any regret (with 1 indicating any regret encompassing the following response options: a little bit, somewhat, quite a bit, or very much) and expressing no regret (with 0 indicating no regret based on the response option: not at all).

Statistical Analysis

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

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; first-order autoregressive was chosen based on Akaike and Bayesian information criteria.[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 disease recurrence. aGVHD was measured as a dichotomous variable indicating whether or not a patient experienced aGVHD by day 100. cGVHD and disease recurrence were tested as time-dependent covariates in predicting regret over the time points of 100 days, 6 months, and 12 months after HCT. Disease recurrence 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. A 2-sided α of .05 was used throughout all analyses. These statistical analyses were completed using Stata statistical software (version 15.1; StataCorp LLC, College Station, Texas).

RESULTS

Comparing Included and Excluded Patients

The 184 patients included in the current study were compared with the 68 patients who were not included because of incomplete regret questions or death occurring before 100 days (see Supporting Table 1). The 2 groups were similar with regard to many characteristics, including age, sex, educational level, Karnofsky performance score, and conditioning regimen intensity. Compared with those patients who were excluded, included patients more often were white and married, with a higher household income and/or reported higher FACT-BMT scores at baseline. Furthermore, these 2 groups also differed with regard to some clinical characteristics, including the Hematopoietic Cell Transplantation Comorbidity Index (HCT-CI) and graft source, with a larger percentage of those patients who were excluded from the analysis having cord blood as their graft source.

Patient Characteristics

Sociodemographic and clinical baseline characteristics of the 184 included patients can be found in Table 1. Approximately 84% of patients were alive at 12 months after HCT. Table 2 describes clinical outcomes, including survival, disease recurrence, cGVHD, and aGVHD by time point. The prevalence of aGVHD at 100 days was 36%, 1% of patients had cGVHD, and 7% of patients developed disease recurrence. Those percentages increased at subsequent time points with cumulative incidences of 43% (95% confidence interval [95% CI], 36%-51%) of patients experiencing cGVHD and 17% (95% CI, 12%-24%) of patients experiencing disease recurrence by 12 months.

Regret Over Time

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

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

Covariance Patterns of Baseline Characteristics With Regret Over Time

Unadjusted covariance pattern models for baseline variables (Table 4) demonstrated that the baseline FACT

TABLE 1. Patient Characteristics (N = 184)

Variable	No. (%)
Median age at transplantation (range), y	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)
Nonwhite	10 (5)
Unknown	2 (1)
Marital status	
Married or living with partner	139 (75)
Single/separated/divorced/widowed	31 (17)
Unknown	14 (8)
Educational level	
≤Secondary education	38 (21)
Vocational/associate's degree	49 (27)
Bachelor's/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)
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 FACT-G 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)
Y of transplantation	
2011	14 (8)
2012	133 (72)
2013	37 (20)
Median clinical follow-up (range), mo	24 (5-38)

Abbreviations: BMT, bone marrow transplantation; CML, chronic myelogenous leukemia; EWB, emotional well-being; FACT-BMT, Functional Assessment of Cancer Therapy–Bone Marrow Transplant; FACT-G, Functional Assessment of Cancer Therapy–General; FWB, functional well-being; HCT, hematopoietic stem cell transplantation; HCT-CI, Hematopoietic Cell Transplantation Comorbidity Index; HL, Hodgkin lymphoma; MDS/MPN, myelodysplastic syndrome/myeloproliferative neoplasms; NHL, non-Hodgkin lymphoma; PWB, physical well-being; RIC/NMA, reduced-intensity conditioning/nonmyeloablative; SWB, social well-being; TOI, trial outcome index; y, years.

subscales SWB (P = .014), BMTS (P = .013), TOI (P = .037), and FACT-G (P = .021) as well as the total FACT-BMT score (P = .012) all were significantly and negatively associated with regret over time. Higher baseline SWB, BMTS, TOI, FACT-G, and FACT-BMT scores significantly reduced the risk of expressing regret at subsequent time points. Patients' HCT-CI was found to be positively and significantly associated with regret over time. Baseline variables that were not found to be significant included age, sex, race, marital status, educational level, income, primary disease, Karnofsky performance score, conditioning regimen intensity, donor, graft source, and year of transplantation.

Unadjusted models demonstrated that post-HCT disease recurrence was a significant risk factor for decisional regret (P = .004), but post-HCT cGVHD was not (P = .88) (Table 4). The risk of regretting transplantation was 17.5 percentage points greater (95% CI, 5.5-29.7 percentage points) in patients who developed disease recurrence after HCT compared with patients who did not develop disease recurrence.

On multivariate analysis, only the baseline FACT-BMT score was found to be significantly associated with post-HCT regret; therefore, the results were not shown. No significant 2-way interactions were found.

DISCUSSION

To the best of our knowledge, the current study is the first to assess the relationship between reporting regret after allogeneic HCT and patient and clinical outcome characteristics over time. We observed a consistent percentage of 6% to 8% of patients expressing regret at each follow-up time point (100 days, 6 months, and 12 months).

TABLE 2. Number and Percentage of Patients Experiencing Clinical Outcomes by Time Point

	Survival	Disease Recurrence	cGVHD
Events occurred before 100 d	—	12 (7%)	2 (1%)
No. for cumulative incidence analysis	184	172	182
6 mo (95% CI)	96% (92%-98%)	8% (4%-12%)	18% (12%-24%)
12 mo (95% CI)	84% (78%-89%)	17% (12%-24%)	43% (36%-51%)

Abbreviations: 95% CI, 95% confidence interval; cGVHD, chronic graft-versus-host disease.
Surviving 100 days was 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%)

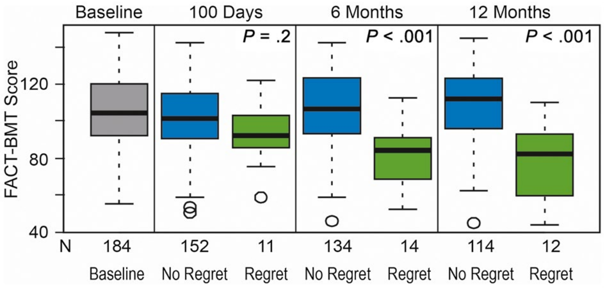

Figure 1. Box plots of Functional Assessment of Cancer Therapy–Bone Marrow Transplant (FACT-BMT) scores at baseline, 100 days, 6 months, and 12 months stratified by those patients who expressed regret and those patients who did not.

This was higher than the previous cross-sectional study of patients reporting regret 12 to 36 months after their transplantation, in which 3% of patients expressed regret, although we did note that in that study, the researchers included those who answered "1" (indicating a little bit) in the category of those not expressing regret.[15] Although conceptually we believe expressing any regret is meaningful, using this operationalization, our sample percentages would be 1% at 100 days, 5% at 6 months, and 2% at 12 months. It is important to note that the patient population in the current study was comprised entirely of individuals who had undergone allogeneic HCT, whereas the patient population in the study by Mosher et al[15] included approximately 60% who had undergone autologous transplantation, which is associated with lower toxicity and no risk of GVHD.

The findings of the current study have suggested a relationship between baseline SWB and later reporting regret about undergoing transplantation. Previous studies have demonstrated frustrations among survivors regarding their social connectedness after transplantation, referencing feelings of guilt because of the impact on their significant others.[21] The current study results suggested it may be those who begin with lower connectedness and SWB who are more at risk of later regret, perhaps due to guilt over impacting a smaller social network. Research in public health and social science has cited social cohesion as a protective factor against poor health outcomes.[22-25]

The findings of the current study regarding baseline SWB extend this literature to suggest that increased social connectedness may serve as a protective factor against later regret regarding health decisions.

Considered a "high-stakes" medical treatment, the decision-making process and, relatedly, the informed consent process for HCT are complex. Patients often are 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 suggested that patients consenting for HCT often later do not recollect the risks and complications explained in consent discussions and, overall, are lacking 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 disease recurrence, to later express regret regarding having undergone transplantation.

Three types of decisional regret have been described: 1) outcome regret, in which the focus of regret is the outcome (ie, disease recurrence); 2) option regret, in which the focus of the regret is the decision chosen (ie, consenting to transplantation); and 3) process regret, in which the focus is on the process leading to the decision (ie, unsuccessful educational process, materials, and/or delivery).[14] Given the data from the current study, we

TABLE 4. Unadjusted Covariance Pattern Modeling Associations Between Baseline Covariates and Regret Over Time

Variable	Coefficient (95% CI)	*P*
Age	−0.002 (−0.005 to 0.001)	.106
Female sex	−0.044 (−0.113 to 0.026)	.219
Nonwhite race	−0.015 (−0.178 to 0.149)	.859
Married or living with partner	−0.075 (−0.171 to 0.021)	.127
Education		
≤Secondary education	Referent	.875
Associate's or vocational degree	−0.013 (−0.116 to 0.090)	.798
≥Bachelor's degree	0.047 (−0.084 to 0.101)	.853
Income ≥$60,000	−0.007 (−0.080 to 0.067)	.858
Primary indication for HCT		
Acute leukemia	Referent	.831
CML	−0.014 (−0.152 to 0.124)	.846
MDS/MPN	−0.013 (−0.103 to 0.078)	.781
Other leukemia	0.013 (−0.114 to 0.139)	.845
NHL	−0.059 (−0.183 to 0.064)	.345
HL	0.112 (−0.118 to 0.341)	.340
Plasma cell malignancy/MM	−0.101 (−0.325 to 0.123)	.376
Karnofsky performance score ≥90	−0.042 (−0.114 to 0.029)	.248
Baseline FACT-BMT score	−0.002 (−0.004 to −0.001)	.012
Baseline PWB subscore	−0.007 (−0.014 to 0.001)	.083
Baseline SWB subscore	−0.011 (−0.020 to −0.002)	.014
Baseline EWB subscore	−0.008 (−0.017 to 0.001)	.055
Baseline FWB subscore	−0.003 (−0.010 to 0.003)	.282
Baseline BMT subscore	−0.008 (−0.013 to −0.002)	.013
Baseline TOI subscore	−0.003 (−0.005 to −0.001)	.037
Baseline FACT-G subscore	−0.003 (−0.006 to −0.001)	.021
HCT-CI	0.026 (0.006 to 0.046)	.011
Myeloablative conditioning regimen	0.006 (−0.063 to 0.076)	.857
Related donor	−0.014 (−0.066 to 0.039)	.602
Graft source		
Bone marrow	Referent	.352
Peripheral blood	0.028 (−0.078 to 0.135)	.605
Cord blood	0.125 (−0.048 to 0.298)	.157
Y of transplantation		
2011	Referent	.156
2012	0.090 (−0.042 to 0.221)	.180
2013	0.142 (−0.005 to 0.288)	.058
Post-HCT aGVHD within 100 d	0.048 (−0.033 to 0.128)	.247
Post-HCT recurrence[a]	0.176 (0.055 to 0.297)	.004
Post-HCT cGVHD[a]	0.008 (−0.091 to 0.106)	.880

Abbreviations: 95% CI, 95% confidence interval; aGVHD, acute graft-versus-host disease; BMT, bone marrow transplantation; cGVHD, chronic graft-versus-host disease; CML, chronic myelogenous leukemia; EWB, emotional well-being; FACT-BMT, Functional Assessment of Cancer Therapy–Bone Marrow Transplant; FACT-G, Functional Assessment of Cancer Therapy–General; FWB, functional well-being; HCT, hematopoietic stem cell transplantation; HCT-CI, Hematopoietic Cell Transplantation Comorbidity Index; HL, Hodgkin lymphoma; MDS/MPN, myelodysplastic syndrome/myeloproliferative neoplasms; MM, multiple myeloma; NHL, non-Hodgkin lymphoma; PWB, physical well-being; SWB, social well-being; TOI, trial outcome index.

A positive coefficient indicates an increased risk of expressing regret over time, whereas a negative coefficient indicates a decreased risk of expressing regret over time.

[a] These clinical outcomes were modeled as time varying.

only were able to formally evaluate the first type, and the findings do point to some patients experiencing outcome regret because disease recurrence was found to be significantly associated with a higher risk of regret over time. Here, the intended outcome of a transplantation (ie, cure from disease) did not occur, but rather disease recurrence occurred, which may have led to regret for undergoing the transplantation. Furthermore, Becerra Perez et al recognized risk factors for decisional regret in their systematic review, and highlighted 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 patients undergoing HCT, making it important to understand how patients came to regret their transplantations. Future qualitative research asking patients why they express regret could help to clarify whether some patients who have undergone transplantation have option regret or process regret, and which risk factors for regret occur among patients undergoing HCT.

Although to our knowledge little research has been done to address regret after HCT, some research points to opportunities in the educational process as having significant potential to mitigate postdecisional regret. It is known that educational materials and delivery methods should be objective and accurate because patients undergoing transplantation 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 transplantation process. Although to our knowledge not formally assessed in the current literature, regret among patients undergoing transplantation likely may stem from education that is not appropriately tailored to the cultural background, barriers to learning, and preferential learning styles of these individuals.[28,30] Future research may use qualitative methods to better understand which type of regret is more prevalent among patients who have undergone transplantation and whether the regret is rooted in dissatisfaction with education, with consenting to transplantation, or something else. In addition, individual centers could ask about regret through their exit surveys years after transplantation, which may broaden our understanding of long-term regret.

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

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CONFLICT OF INTEREST DISCLOSURES

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AUTHOR CONTRIBUTIONS

Rachel N. Cusatis, **Heather R. Tecca**, **Anita D'Souza**, **Bronwen E. Shaw**, and **Kathryn E. Flynn** were responsible for the design and execution of the study and wrote the article. **Heather R. Tecca** performed the analyses. All authors approved the final draft of the article.

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