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Barriers to Psychological Care among Primary Caregivers of Children undergoing Hematopoietic Stem Cell Transplantation

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Abstract

Purpose—This substudy of an intervention trial aimed to describe barriers to participation in psychological care among primary caregivers of children who were about to undergo a Hematopoietic Stem Cell Transplantation (HSCT), including demographic and medical correlates.

Method—Three hundred and twelve primary caregivers of children undergoing HSCT who were approached to participate in a psychological intervention trial (n = 218 enrollees and 94 decliners) completed a measure of barriers to psychological care.

Results—The most frequently endorsed barriers to care were focusing on the child as priority, not wanting to leave the child's bedside, and already having adequate psychosocial support. The least frequently endorsed barriers were location, wait times, and stigma around seeking psychological care.

Conclusions—Results suggest that explaining how psychological care for a primary caregiver can positively affect their ill child may reduce barriers to seeking needed support services. Certain practical barriers to care may be irrelevant in inpatient settings where psychological support is offered.

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Conflict of Interest

The authors declare no conflicts of interest.

Ethical approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Introduction

Hematopoietic stem cell transplant (HSCT) offers a potential life-saving treatment to children with various hematologic and oncologic diseases. This procedure can be physically demanding because it entails preparatory regimens of chemotherapy and/or radiation, prolonged hospital stays, and increased risk of infection following the HSCT [1]. The risk of mortality associated with HSCT is high, depending on the type of HSCT (autologous vs. allogeneic) and the type of donor [2]. If the child survives HSCT, short- and long-term medical effects such as graft-versus-host disease, cardiovascular disease, pulmonary disease, renal disease, endocrine disease, bone density problems, neurocognitive deficits, and/or other cancers are relatively common, with up to 50% of survivors reporting one or more late effect after HSCT [3].

Given the medical risks associated with HSCT, it is not surprising that many primary caregivers experience psychological distress at the time of their child's HSCT [4–7]. Indeed, estimates suggest that up to 20% of mothers experience clinically significant distress reactions such as depression and anxiety at the time of HSCT [5, 8]. These distress reactions persist; between 14% and 33% of parent caregivers report clinically significant levels of anxiety, depression, and/or post-traumatic stress in the years after their child's HSCT [8, 9].

Despite the recognized need for caregiver support due to the distress experienced during and following their child's HSCT, very few caregivers seek out psychological services [10]. Yet, almost 60% of caregivers recommended resources for “emotional issues of caregivers” as “must have” resources during the HSCT process [10]. Unfortunately, studies have not systematically explored reasons caregivers do not seek out supportive care services. Generally, research about barriers to psychological care has focused on parents seeking family or child-focused services [11], adults with cancer [12], or adults with mental health issues [13]. Research with adult cancer patients has demonstrated underuse of psychological care, with patients endorsing practical and emotional barriers to psychological care [12]. Parallel work has not been done in caregivers of pediatric patients. A close comparison is acceptance rates of psychological intervention research studies for caregivers of pediatric cancer patients, which are low to modest (23% to 54%) in some studies [14–17] and high (75% to 92%) in others [18–20]. Reasons for not participating include lack of time [16, 19, 21], feeling overwhelmed [19], competing medical care priorities [22], and not wanting to separate from the child [14]. These studies have typically collected a single reason for non-participation in a research study of a psychological intervention, leaving a gap in our understanding of the range of barriers that impede caregiver uptake of psychological care more broadly. Understanding these barriers and correlates of these barriers can lead to interventions that can inform caregivers about the benefits of psychosocial care to address their emotional and psychosocial needs [23, 24].

The current substudy sought to advance our understanding of barriers to participation in psychological care by systematically using a standardized instrument of barriers to care and examining demographic and medical correlates of barriers to care. Data were collected from primary caregivers who were approached to participate in a psychological intervention trial. We hypothesized that barriers specific to pediatric patients, including reluctance to leave the

child's bedside and a focus on the child's needs rather than parental needs, would be frequently endorsed by parents. Our analysis of demographic and medical correlates of barriers to care was exploratory, but we expected parents with lower socioeconomic status to report higher levels of barriers to psychological care given prior work in family therapy [11].

Method

Participants

Participants were primary caregivers of children undergoing HSCT who were approached for participation in a randomized trial of a psychological care intervention to reduce caregiver distress following a child's HSCT. Those who agreed to enroll in the trial ($n = 218$) and those who declined the trial but agreed to participate in this barriers survey substudy ($n = 94$) completed a measure of barriers to psychological care. Following completion of baseline surveys, trial participants were randomized either to the Parent Social-Cognitive Processing Intervention Program (P-SCIP) or standard psychosocial care [Manne et al., submitted for publication]. P-SCIP consisted of five hour-long sessions and an interactive CD-ROM program targeting relaxation, problem solving, child behavioral problems, cognitive restructuring, communication, and post-HSCT concerns. Standard psychosocial care consisted of the standard inpatient child-focused social work and psychology/psychiatry services available at all participating sites (also available to P-SCIP participants) plus a single meeting where the caregiver was provided a pamphlet and video about coping with HSCT, a walkie-talkie for communication with the child, and five optional hours of respite care (to equate for the five hours spent in intervention sessions).

Recruitment occurred at four pediatric HSCT centers in the US. All centers offered psychosocial support services for the child and parent during the HSCT inpatient hospitalization as standard care. Eligibility criteria included: 1) primary caregiver (i.e., the parent or guardian self-identified as taking primary responsibility for child's care during the HSCT) of child under 19 years of age who was scheduled for HSCT within the next month; 2) diagnosis of the pediatric patient must not be medulloblastoma or other cancer of the brain (because of vastly differing survival rates for these patients); 3) participant had phone service (for follow-ups); and 4) caregiver spoke, read, and wrote English or Spanish (participation in Spanish was available at two of the four sites where a large proportion of the patient population was Spanish-speaking).

Of the 507 caregivers approached, 126 were ineligible (24.9%). A total of 230 caregivers (60.4%) consented to the psychosocial intervention study and 151 caregivers (39.6%) declined to participate. However, 12 caregivers who consented dropped from the trial prior to baseline, resulting in 218 caregivers (57.2%) who participated. Two of the four sites had lower acceptance rates for the main psychosocial intervention study (50–53% vs. 62–69%, $p < .001$), and there were some expected demographic differences between participants at the different sites that were representative of the catchment areas of each site (e.g., the two sites that enrolled Spanish-speaking families had higher percentage of Hispanic/Latino participants). Of the 151 who declined the main intervention study, 94 consented to participate in this substudy examining barriers to psychological care (62.3%) and 57 declined both the main study and the substudy (37.7%). Reasons for declining both studies

included not being interested ($n = 18$), being overwhelmed/stressed/tired ($n = 11$), believing the study would take too much time ($n = 4$), not wanting to leave the child's bedside ($n = 3$), and other reasons ($n = 6$). Many passively declined without giving a reason ($n = 15$). There was an association between participant status (main participant vs. substudy participant vs. total study decliner) and parent sex, $X^2(2) = 7.32, p = .03$, race/ethnicity, $X^2(6) = 18.5, p = .01$, child diagnosis, $X^2(4) = 10.1, p = .04$, and child type of HSCT, $X^2(2) = 11.0, p = .004$. Compared with main study and barrier substudy participants, total study decliners were more likely to be male, of Non-Hispanic Other race/ethnicity, and to have a child with a blood-related cancer diagnosis or who was receiving an allogeneic transplant. Table 1 shows characteristics of the sample completing the barriers substudy.

Measures

Demographic and medical factors—Participants completed a measure of demographic information including age, relationship to patient, marital status, education, income, race/ethnicity, child age, child gender, and child race/ethnicity. Medical factors, including diagnosis, HSCT type, and HSCT date were abstracted from medical records. Diagnosis was categorized as “Blood-related cancers,” “Non-blood-related cancers,” or “Non-cancer.” Acceptance or refusal of participation in the larger intervention trial was conceptualized as a history of acceptance or refusal of psychological care services.

Barriers to participation in psychological care—The Awareness and Barriers to Counseling-Revised (ABC-R)[12] is an 18-item scale assessing awareness of, attitudes about, and barriers to the use of psychological care [12, 25]. Definitions of psychological services, anxiety and distress symptoms, and cognitive-behavioral therapy are provided and then caregivers are asked to rate the extent to which each statement may impact his/her decision to obtain psychological services related to worries or concerns about his/her child's HSCT using a nine-point scale from 0 = *Do not agree at all* to 8 = *Agree extremely*. The ABC-R has demonstrated adequate reliability (total score Cronbach's alpha = .84) and validity [12]. As this measure was originally developed for adult cancer patients, we modified the wording of items to refer to having a child with an illness rather than having the illness oneself. Additionally, the item “My child may feel too ill” was adapted to include “and I do not want to leave his or her side to go to a counseling session” to reflect this specific barrier noted by parents of children with cancer [26]. The last item is open-ended, allowing the participant to add and rate a barrier but is not scored. Given that this was the first systematic examination of various barriers to psychological care among caregivers of pediatric HSCT patients and that we conceptualized barriers as multidimensional constructs in which a respondent's perception of one barrier does not necessarily predict the same respondent's perception of another barrier [27], we chose to analyze individual items as well as an overall total barriers score (Cronbach's alpha = .76).

Procedures

This study was approved by the Institutional Review Boards at each site. Research assistants identified potentially eligible caregivers at the time of preparatory consultation for HSCT when the decision for HSCT had been made and a donor identified. Caregivers who declined to participate in the psychological intervention study were asked to participate in this

substudy examining barriers to psychological care. Informed consent and authorization to abstract medical data were obtained from participants. Intervention study participants completed the Awareness and Barriers to Counseling survey (ABC-R) and demographic information as part of the larger baseline assessment. Barrier substudy participants completed only these measures. Spanish translation for all study materials was accomplished by using a translation/back-translation approach by independent translators.

Statistical Analysis

Preliminary examination of the main outcome and covariates indicated that 35 of the 312 participants (11%) were missing responses to at least one barrier item, and an additional three participants (1%) were missing covariate responses. Given that an index score could be biased by missing items, we chose to analyze only complete observations ($n = 277$).

Barriers to psychological care were descriptively characterized by examining means and standard deviations for the total barriers index score (summary of responses to all 17 items on the ABC-R) and for individual items (Aim 1). The percentage of parents who rated an item as at least “somewhat” of a barrier (i.e., score of 4 or higher on the 0 to 8 scale) is also reported. To evaluate demographic and medical correlates of barriers (Aim 2), linear models examined the effects of demographic and medical covariates and psychological intervention study acceptance status on the barrier index. *P*-values from Type III *F* tests indicate whether the effect of each variable was statistically significant when unadjusted (univariate models) or when adjusted for the remaining covariates (multivariate models).

Because an index may obscure the effects of covariates on individual barriers, we employed a multivariate analysis of variance (MANOVA) with Wilks’ lambda to evaluate whether any of the 17 barriers were related to each demographic and medical covariate, unadjusted and adjusted for the remaining covariates. The MANOVA accounts for the multiple testing for the collection of responses. Post hoc analysis of variance (ANOVAs) identified which individual barriers were associated with the covariates selected through MANOVAs. Only those with *p* values below .05 for both the unadjusted (univariate) and adjusted (multivariate) analyses were interpreted.

Results

Barriers to Participation in Psychological Care

The overall sample mean on the total barriers index score was 38.9 ($SD = 19.2$, range = 2–109). Descriptive information for each item is shown in Table 2. The barriers most frequently endorsed were “My time and energy are focused on my child’s treatment” (92.8%), “My child may be too ill and I do not want to leave his or her side to go to a counseling session” (82.3%), and “I get all the support I need from other sources” (59.2%). The descriptor corresponding to the average rating of these barriers ranged from “agree somewhat” to “moderately agree.” The barriers least frequently endorsed were “I would have to wait too long to get an appointment for mental health services” (7.6%), “I would be too embarrassed to seek mental health services” (7.9%), and “The location is inconvenient”

(13.0%). The descriptor corresponding to the average rating of these barriers was slightly above “do not agree at all.”

Medical and Demographic Correlates of Barriers to Psychological Care

Table 3 shows the results summarizing the effects of demographic and medical covariates on (1) the index through linear regression and (2) the collection of barriers through MANOVA. Overall very few demographic and medical variables were associated with barriers. Age was the only factor associated with the index score. Psychological intervention acceptance status, race/ethnicity, and education were significant covariates in the MANOVA, indicating that these characteristics are predictive of at least one of the 17 barriers included in the index. Follow-up ANOVAs indicated that psychological intervention acceptance status was predictive of barrier items 9 (“I am too busy”), 12 (“I get all the support I need from other sources”), 14 (“I have never heard of Cognitive-Behavioral Therapy”), and 16 (“I am concerned that my insurance company would not cover bills for mental health services”) in both unadjusted and adjusted models (adjusted for all other covariates), $p < .01$. Caregivers who declined to participate endorsed being “too busy” ($M = 4.6$ vs. 2.6) and already having adequate support ($M = 5.3$ vs. 3.5) to a greater degree than those who agreed to the trial, but the opposite pattern emerged for lack of knowledge about cognitive-behavioral therapy ($M = 1.9$ vs. 3.5) and insurance concerns ($M = 1.1$ vs. 2.2).

Race/ethnicity was associated with item 16 (“I am concerned that my insurance company would not cover bills for mental health services”) after adjusting for all other covariates ($p = .0032$). Caregivers of Non-Hispanic Black race/ethnicity reported the lowest score on this item compared to caregivers of other races ($M = 1.1$ for Non-Hispanic Black vs. 2.3 for Non-Hispanic White vs. 2.1 for Non-Hispanic Other vs. 1.8 for Hispanic/Latino). Education was associated with item 3 (“I don’t have transportation”) after adjusting for all other covariates ($p = .0052$). Caregivers with a high school education or less endorsed this item to a greater degree than caregivers with some college or a four-year college degree or above ($M = 2.1$ vs. 0.8 vs. 0.5).

Discussion

This was the first study to examine barriers to seeking caregiver-focused psychological care among primary caregivers of children undergoing HSCT. The most frequently endorsed and strongly rated barriers were focusing time and energy on the child’s needs and not wanting to leave the child’s bedside. Additionally, consistent with other studies [12], caregivers endorsed having adequate social support as a reason for not seeking care. The barriers with the lowest endorsement were location, waiting time, and embarrassment about seeking counseling. Although the literature on adults with mental health issues has found practical barriers and stigma to inhibit seeking services [28], these barriers are not as relevant in the context of pediatric HSCT. Like the centers in our study, most transplant centers offer universal support services that extend to the family of the child undergoing HSCT [29, 30]. The increased attention to psychosocial needs of the child and family in recent decades has likely created a culture where psychological care for parents and child is less stigmatized, but barriers remain for the parent seeking self-focused care.

Given caregivers' prioritization of the child, it may be helpful to frame a recommendation for the parent to obtain psychological care in the context of how such care will be helpful for the child. Parent psychological functioning is inextricably linked to child functioning [31, 32], and discussing that point may reduce parents' concern that obtaining psychological care would take energy away from assisting their child. Offering respite care for the parent to attend a psychological session may reduce concern about leaving the child's bedside. Online interventions may be particularly useful in circumventing this barrier, as such sessions could be completed by the parent at the child's bedside. Improving caregiver participation in intervention research is important for evaluating the efficacy of interventions and moving towards evidenced-based standards of psychosocial care for families of children with cancer [33].

Very few demographic and medical variables were associated with barriers to psychological care, suggesting that a routine screening of barriers to psychological care may be necessary to understand challenges caregivers face in obtaining care. The positive correlation between older age and greater barriers was consistent with other work showing a negative correlation between age and the desire for psychological care [34]. A lack of significant associations between medical factors and barriers is consistent with prior work demonstrating a lack of association between objective medical factors and parent psychological outcomes [35–37], though recent work showed that parents' emotional functioning was negatively affected by HSCT complications [38]. Further, treatment intensity has demonstrated a low but positive correlation with psychosocial resource use during pediatric cancer treatment [39].

Examination of individual barriers also yielded few significant associations. One exception was parents' acceptance or refusal of the main psychological intervention study. Caregivers who declined to participate in the psychological intervention were more likely to report being too busy and already having adequate support. These barriers are consistent with reasons for decline of this total study (i.e. main psychological intervention trial and barriers substudy), as well as previous reports of reasons for declining psychological intervention studies [16]. For primary caregivers who already have adequate support, declining psychological care may be appropriate.

On the other hand, caregivers who enrolled in our psychological intervention trial reported greater lack of knowledge of a cognitive-behavioral intervention and insurance payment concerns. Since this was a cross-sectional study, these associations may indicate that caregivers agreed to the psychological intervention trial because it was free (eliminating potential insurance barriers) and the informed consent process explained the cognitive-behavioral intervention offered (overcoming lack of knowledge as a barrier). Having a member of the treatment team routinely provide information about all psychological care services available eliminates lack of knowledge and awareness of options as barriers to care.

Although this study was the first to systematically characterize caregiver barriers to psychological care, there were several limitations. This was a cross-sectional study with caregivers recruited immediately prior to HSCT; we did not follow caregivers who did not enroll in our intervention study to assess psychological care use. The ABC-R was not previously validated in Spanish. Also, our measure of marital status did not allow for

respondents to indicate if they were partnered but not married, which created a heterogeneous “single/never married” group of individuals with and without unmarried partners. Additionally, we did not measure psychological distress among substudy participants. Although distress has been inconsistently related to the desire for and the use of psychological care services [12, 34, 39, 40], future research should examine associations among caregiver distress, barriers to care, and the use of psychological care. Future work should also incorporate other relevant factors such as child distress and caregivers’ unmet support needs [24].

In conclusion, the most frequently endorsed caregiver perceived barriers to psychological care were focusing on the child as priority, not wanting to leave the child’s bedside, and believing that they already had adequate psychosocial support. The least frequently endorsed barriers were practical barriers such as location and transportation, which were not relevant to caregivers residing in an inpatient unit, as well as stigma associated with psychological care. These results suggest that explaining how psychological care for a primary caregiver can positively affect their ill child may improve caregivers’ understanding of the relevance of such treatment to their own and their child’s long-term well-being and may reduce barriers to seeking needed support services. Additionally, researchers and clinicians should explore whether offering psychological support services at different time points in the treatment process or via web-based formats, reducing the barrier of leaving the child’s bedside, would benefit primary caregivers.

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Figure 1.
Consort flow diagram of study enrollment.

Table 1

Demographic and medical characteristics of the sample

Characteristic	Intervention Study Participants (<i>n</i> = 218)	Barrier Substudy Participants (<i>n</i> = 94)	Difference Test <i>p</i>
Caregiver Age (years) <i>M</i> (<i>SD</i>)	37.4 (8.1)	37.7 (7.6)	.78
Caregiver Sex			
Female	199 (91.3%)	85 (90.4%)	.81
Male	19 (8.7%)	9 (9.6%)	
Relationship to Patient ^a			
Mother	192 (88.1%)	85 (90.4%)	.16
Father	18 (8.3%)	9 (9.6%)	
Other (e.g., Grandparent)	8 (3.7%)	0 (0%)	
Caregiver Education			
High School or Less	55 (25.2%)	23 (25.0%)	.49
Some College/2-Yr Degree	80 (36.7%)	28 (30.4%)	
Completed 4-Yr Degree/More	83 (38.1%)	41 (44.6%)	
Caregiver Marital Status			
Married	151 (69.3%)	75 (79.8%)	.14
Separated/Divorced/Widowed	33 (15.1%)	8 (8.5%)	
Single/Never Married	34 (15.6%)	11 (11.7%)	
Caregiver Race/Ethnicity			
Non-Hispanic White	102 (46.8%)	58 (61.7%)	.01
Non-Hispanic Black	54 (24.8%)	15 (16.0%)	
Non-Hispanic Other	17 (7.8%)	12 (12.8%)	
Hispanic/Latino	45 (20.6%)	9 (9.6%)	
Household Income ^b			
\$0 – \$19,999	41 (19.5%)	16 (20.8%)	.32
\$20,000 – \$39,999	59 (28.1%)	13 (16.9%)	
\$40,000 – \$59,999	25 (11.9%)	11 (14.3%)	
\$60,000 – 79,999	23 (11.0%)	11 (14.3%)	
\$80,000 & above	62 (29.5%)	26 (33.8%)	
Child Age (years) <i>M</i> (<i>SD</i>)	8.5 (5.3)	8.0 (5.3)	.47
Child Sex			
Female	95 (43.6%)	40 (42.6%)	.87
Male	123 (56.4%)	54 (57.4%)	
Child Race/Ethnicity			
Non-Hispanic White	96 (44.0%)	52 (55.3%)	.05
Non-Hispanic Black	54 (24.8%)	15 (16.0%)	
Non-Hispanic Other	20 (9.2%)	13 (13.8%)	
Hispanic/Latino	48 (22.0%)	13 (13.8%)	
Child Diagnosis			
Cancer, Blood-Related	116 (53.2%)	48 (51.1%)	.12

Characteristic	Intervention Study Participants (<i>n</i> = 218)	Barrier Substudy Participants (<i>n</i> = 94)	Difference Test <i>p</i>
Cancer, Non-Blood	30 (13.8%)	21 (22.3%)	
Non-Cancer	72 (33.0%)	24 (25.5%)	
Type of Transplant			
Autologous	40 (19.2%)	25 (32.1%)	.02
Allogenic	168 (80.8%)	53 (67.9%)	

Note.

^a Fisher's exact test used due to expected cell count less than 5.

^b Income was categorized into three categories, 1 = \$0–39,999, 2 = \$40,000–79,999, and 3 = \$80,000 & above for analyses.

Table 2Descriptive information of caregivers' barriers to psychological care ($n = 277$)

Barrier Item	Total Sample <i>M (SD)</i>	% Who Agreed Somewhat to Strongly ^a
1. My child may feel too ill and I do not want to leave his or her side to go to counseling sessions	5.75 (2.58)	82.3%
2. Mental health services are offered at inconvenient times	1.58 (2.36)	22.4%
3. I don't have transportation	1.03 (2.39)	14.8%
4. My time and energy are focused on my child's treatment	6.68 (1.94)	92.8%
5. Mental health services can be more upsetting than helpful	1.94 (2.36)	29.6%
6. Mental health services are not relevant to dealing with my child's medical treatment	1.70 (2.37)	22.4%
7. I am uncomfortable seeking counseling	1.41 (2.37)	21.7%
8. The location is inconvenient	0.91 (2.14)	13.0%
9. I am too busy	3.22 (3.03)	49.1%
10. I don't know enough about it	1.84 (2.57)	27.4%
11. I didn't know it existed	1.35 (2.57)	20.2%
12. I get all the support I need from other sources	3.98 (2.95)	59.2%
13. My doctor/nurse/health care provider didn't tell me about mental health services	1.45 (2.59)	19.9%
14. I have never heard of cognitive behavior therapy	3.04 (3.48)	40.1%
15. I have to wait too long to get an appointment for mental health services	0.59 (1.65)	7.6%
16. I am concerned that my insurance company would not cover bills for mental health services	1.92 (2.88)	26.7%
17. I would be too embarrassed to seek mental health services	0.69 (1.72)	7.9%

Note.

^a Agreed somewhat to strongly was equivalent to a score of 4 to 8 (total scale 0 to 8).

Table 3

Univariate and multivariate effects using both the barrier index as a univariate response and items 1 through 17 as a multivariate response

	Barrier Index in linear regression: <i>P</i> -value from F-test		Items 1 through 17 in MANOVA: <i>P</i> -value from Wilks Lambda	
	Univariate	Multivariate	Univariate	Multivariate
Psychological Intervention Acceptance Status	.96	.48	<.0001	<.0001
Caregiver Sex	.081	.40	.0016	.094
Caregiver Race	.55	.68	.0029	.034
Caregiver Marital Status	.40	.62	.038	.29
Caregiver Age	.0067	.0020	.034	.26
Caregiver Education	.40	.66	<.0001	.018
Family Income ^a	.15	.011	.0002	.28
Other Siblings	.14	.16	.53	.85
Cancer Diagnosis	.68	.45	.0002	.20
HSCT Type ^b	.37	.45	.16	.94

Note. The multivariate models were adjusted for all other covariates listed in the table. N = 277 except where noted.

^aThe univariate analysis for income was conducted with 252 observations;

^bThe univariate analysis for HSCT type was conducted with 255 observations. HSCT types were categorized as autologous or allogeneic.