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ORIGINAL ARTICLE

Validating the positive impact of in-hospital lay care-partner support on patient survival in allogeneic BMT: a prospective study

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This prospective study validates the finding from retrospective research that having an inpatient lay care-partner (CP) is associated with better survival following allogeneic BMT. Compared with patients without a CP ($n = 76$), patients with a CP ($n = 88$) have significantly better OS ($P = 0.017$) and relapse-free survival (RFS) ($P = 0.020$). Four-year and median survivals were 42% and 36 months among patients with CPs, compared with 26% and 10 months among those without CPs. Four-year survival and median RFS were 39% and 25 months among those with CPs, compared with 23% and 7 months among those without CPs. Further, better survival and RFS were associated with CP visit duration of >3 h per day ($P = 0.005$ and $P = 0.007$, respectively) and with CP frequency of visits $>75\%$ of inpatient days ($P = 0.004$ and $P = 0.010$, respectively). A CP support program should encourage not only presence of a CP but also duration and frequency of CP visits associated with better patient survival.

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INTRODUCTION

Retrospective research demonstrates that having a consistent in-hospital lay care-partner (CP) during the inpatient stay for allogeneic BMT is associated with significantly improved patient survival.[1] Although lack of a CP and of adequate social support were both significant risk factors for death in univariate analysis, only CP status remained significant in multivariable analysis; disease in remission, a matched-related donor, and diagnosis of lymphoma were significant biomedical prognostic factors. When quantifying the relative contribution of each of the four risk factors for death in the multivariable model, not having a CP contributed 44% of the total value.

That not having a CP was comparable with biomedical risk factors for mortality was an unexpected finding. This led to the present prospective study to validate and examine the CP phenomenon in more depth.

Undergoing cancer treatment is a traumatic experience,[2–4] and allogeneic BMT patients without a CP are more likely to feel traumatized by treatment and may experience an existential crisis,[5] questioning the very essence of their existence. The literature on existential concerns of oncology patients reveals that the struggle to maintain self-identity and threats to self-identity are important themes.[6] Vulnerable patients cope by turning to close relationships. Married oncology patients have better survival rates than single, divorced or widowed patients.[7–9] Among women with breast cancer, having a confiding dependable relationship, involving emotional processing associated with psychological well-being,[10] is a protective effect against mortality.[11,12] Such meaningful social encounters are theorized to create safety and a '… sense of comfort that helps explain why the effect of one person on another is so potent'.[13] This may also contribute to the placebo effect,[14,15] immune functioning,[16] and the release of restorative hormones.[17] Similarly, one might expect that such a close relationship for allogeneic BMT patients would serve to maintain self-identity, promote a sense of well-being and have a positive influence on survival.

There is also evidence that having family or social support systems may not compensate for the lack of a confiding relationship between patient and partner,[10,18] which is consistent with findings in retrospective research on the survival value of having an in-hospital CP.[1] Therefore, support from a designated CP may be qualitatively different and exert more influence on survival than general social support. This premise, along with CP status being found comparable to established biomedical risk factors for mortality, remains to be validated. Furthermore, in as much as an in-hospital CP's participation varies in terms of duration and frequency of visits, levels of confiding and dependability in the CP-patient relationship will vary as well.

We further examined the prognostic value of CPs by conducting a five year prospective study with the primary objective of validating the positive influence of in-hospital lay CPs on patient survival in allogeneic BMT. Additionally, we sought to validate the impact of CP support compared with biomedical and other psychosocial risk factors such as family or support system availability and stability. We also explored the impact of duration and frequency of in-hospital CP visits on patient survival.

MATERIALS AND METHODS

The Cleveland Clinic Institutional Review Board (IRB) approved the prospective CP study. The study includes baseline demographic and medical data, and post-transplant medical outcomes on 164 adult (age $\geqslant 18$) allogeneic patients who underwent transplant at the Cleveland Clinic from November 2003 to November 2008. Each patient and participating CP was asked to enroll in the study and sign an informed consent. Beyond the 164 study patients, there were 21 patients who enrolled but who never came to BMT due to worsening medical condition

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or death; 28 patients were not enrolled because of illiteracy ($n=3$), inability to comprehend study description ($n=2$), language barriers ($n=1$), being hospitalized on an acute care hospital floor ($n=6$), and patient or CP not willing to participate ($n=16$). All study patients were treated on medical protocols approved by the Cleveland Clinic IRB.

A 24 h CP post-discharge is required of every allo-transplant patient. It is also a program requirement that patients coming for pre-transplant evaluation appointments be accompanied by the primary person planning on being their CP. A consistent in-hospital lay CP was defined as one person who planned on being with the patient five or more days a week, beginning the day of admission to the inpatient BMT Unit. CPs self-identified whether or not they would be in the in-hospital CP group; the definition of lay CP was based on intent and those who did not follow-up as agreed were not switched to the no CP group, but were followed in terms of duration and frequency of participation. The number of days and the amount of time each day in-hospital lay CPs stayed with the patient were recorded in a weekly log kept by the CP and collected weekly by the BMT social worker.

To determine whether support from a primary CP is qualitatively different than family or social system support, as well as further describe the patient population, the psychosocial assessment of candidates for transplantation (PACT) scale[19] was completed on each patient by an oncology social worker. The PACT scale rates patient quality of candidacy for transplant from a psychosocial risk perspective using eight Likert-type rating scales grouped under social support, psychological health, lifestyle factors, understanding of transplant and follow-up.

Statistical analysis

Study size calculations were based on ability to detect an absolute improvement of 25% in 1 year survival between patients with and without a CP. The calculation was based on a two-sided test with 5% significance, and assumed that percentage of patients with and without a CP would be similar to that from the retrospective study. The calculation revealed 150 patients were needed to have 89% power to detect a 25% survival difference. Accrual was continued beyond 150 patients to compensate for potential deviations from assumptions used to make the calculations.

Nominal categorical variables were summarized as frequency counts and percentages and compared between CP and no CP groups using χ^2-test. Continuous variables or ordinal categorical variables were summarized as the mean, s.d., median, minimum and maximum, and compared between groups using the Wilcoxon rank-sum test.

Relapse, survival and relapse-free survival (RFS) were calculated relative to transplant date. Outcomes were estimated using the Kaplan–Meier method and compared between groups using the log-rank test. Cox proportional hazards analysis was used to identify univariable and multivariable prognostic factors for survival and RFS. For the multivariable analysis, a stepwise selection procedure was used with a variable entry criterion of $P\leqslant 0.10$ and a variable retention criterion of $P\leqslant 0.05$. Results were summarized as the hazard ratio (HR), 95% confidence interval for the HR, and the corresponding *P*-value. In these analyses, $HR>1$ indicates a higher risk of the event corresponding to each outcome and $HR<1$ indicates a lower risk. The event for survival is all cause mortality and the events for RFS are relapse or all cause mortality. Twenty-four variables were analyzed as potential prognostic factors: CP status, gender, race, age, children, employment status, number of prior chemotherapy regimens, prior radiation therapy, co-morbidity index, active disease, primary diagnosis, HLA match, donor relationship, preparative regimen, sources of hematopoietic cells, CD34+ dose and eight PACT scale items.

CP visitation duration was calculated as the average number of hours per day that the CP spent with the patient. Frequency was calculated as the percentage of days the CP spent any time with the patient. Duration and frequency were 0 for patients with no CP. Recursive partitioning analysis was used to identify optimal cut-points in duration or frequency of CP visitation that best predict survival or RFS. Kaplan–Meier estimates of survival and RFS were compared by duration and frequency using the log-rank test. Data were analyzed using SAS software (SAS Institute Inc., Cary, NC, USA). All statistical tests were two sided, and $P\leqslant 0.05$ was used to indicate statistical significance.

RESULTS

Patient and transplant characteristics by CP status

Of the 164 study patients, 88 (54%) had a lay CP and 76 (46%) had no CP. Patients with a CP were significantly less likely than patients without a CP to have children ($P=0.005$). There were no other significant differences between the two patient groups; noteworthy, but not reaching statistical significance ($P=0.09$), was the finding that patients without a lay CP had more inpatient readmission days (Table 1).

PACT scale by CP status

Of the eight PACT Scale items, there were significant differences between the two groups on six items. Patients having a CP had a significantly more favorable rating on: family or support system stability ($P<0.001$); family or support system availability ($P<0.001$); psychopathology, stable personality factors ($P=0.05$); risk for psychopathology ($P=0.013$); healthy life-style, ability to sustain change in life-style ($P=0.007$); and understanding of transplant and follow-up: relevant knowledge and receptiveness to education ($P=0.025$). Noteworthy but not reaching statistical significance is the association between having a CP and better patient compliance with medications and medical advice ($P=0.06$) (Table 2).

CP characteristics

Sixty-eight percent of CPs were female. Most (60%) were the patient's spouse, 29.5% were a parent and 2% each were a sibling or an adult child. 87.5% of CPs lived with the patient prior to admission. 66% of CPs were employed and 56% had attended college (Table 3).

Patient outcomes by CP status

Relapse did not differ significantly between groups ($P=0.54$). Non-relapse mortality was higher among patients without a CP ($P=0.003$), but relapse mortality was similar between groups ($P=0.81$). Survival ($P=0.017$; Figure 1) and RFS ($P=0.020$; Figure 2) are better among patients with a CP. Four-year and median survival were 42% and 36 months among patients with CPs, compared with 26% and 10 months among those without CPs. Four-year survival and median RFS were 39% and 25 months among those with CPs, compared with 23% and 7 months among those without CPs.

Univariable and multivariable prognostic factors

Among 16 baseline characteristics and eight PACT scale items, seven variables were prognostic for survival in univariable analysis: not having a CP (HR 1.61, $P=0.018$), employment status of disabled (relative to employed; HR 1.60, $P=0.030$), PACT scale rating on family or support system availability (HR 0.79, $P=0.042$), PACT scale rating on understanding of transplant and follow-up (HR 0.78, $P=0.019$), high-risk hematopoietic cell transplantation-specific co-morbidity index (HR 1.76, $P=0.019$), HLA mismatch (HR 1.67, $P=0.044$) and cord blood transplant (HR 2.19, $P=0.048$). Variables remaining prognostic in multivariable analysis are: no CP ($P=0.022$), PACT scale rating on understanding of transplant and follow-up ($P=0.019$), high-risk hematopoietic cell transplantation-specific comorbidity index ($P=0.036$) and HLA mismatch ($P=0.013$) (Tables 4 and 5).

Four variables were prognostic for RFS in univariable analysis: not having a CP (HR 1.56, $P=0.021$), PACT scale rating on family or support system availability (HR 0.78, $P=0.026$), PACT scale rating on understanding of transplant and follow-up (HR 0.80, $P=0.024$) and HLA mismatch (HR 1.63, $P=0.05$). Three variables remained prognostic for RFS in multivariable analysis: not having a CP ($P=0.023$), PACT Q8: understanding of transplant and follow-up ($P=0.024$) and HLA mismatch ($P=0.015$).

Patient outcomes by CP duration and frequency

Among 88 patients with a CP, median duration of daily visitation was 6.5 h (range 0.6–22.7), and median frequency of daily

Table 1. Patient and transplant characteristics by CP status

Variable	*No CP* (n = *76*)		*CP* (n = *88*)		P-*value*
	N	%	N	%	
Female gender	41	53.9	42	47.7	0.43
Race					
White	62	81.6	81	93.2	0.08
Black	11	14.5	5	5.7	
Other	3	3.9	1	1.1	
Age, years					
Mean ± s.d.	41 ± 12		41 ± 13		0.75
Median (range)	42 (18–65)		45 (19–61)		
Has children	59	77.6	50	56.8	0.005[a]
Employment status (other is retired, stay at home parent, student or unemployed)					
Employed	31	40.8	40	45.5	0.33
Disabled	38	50.0	35	39.8	
Other	7	9.2	13	14.8	
Number of prior chemotherapy regimens					
Mean ± s.d.	2.3 ± 1.6		2.0 ± 1.3		0.43
Median (range)	2 (0–9)		2 (0–6)		
Had prior radiation therapy	3	3.9	6	6.8	0.42
Co-morbidity index, HCT-CI					
Low risk	24	31.6	33	37.5	0.58
Intermediate risk	28	36.8	26	29.5	
High risk	24	31.6	29	33.0	
Active disease at transplant	40	52.6	37	42.0	0.18
Primary diagnosis					
AML	38	50.0	44	50.0	0.95
ALL	13	17.1	18	20.5	
MDS	11	14.5	11	12.5	
CML	6	7.9	8	9.1	
Other	8	10.5	7	8.0	
HLA matched	64	84.2	75	85.2	0.86
Unrelated donor	45	59.2	42	47.7	0.14
Preparative regimen					
TBI + chemo	25	32.9	34	38.6	0.80
BU/CY	40	52.6	45	51.1	
BU/CY/Etoposide	10	13.2	8	9.1	
CY/ATG	1	1.3	1	1.1	
Source of hematopoietic cells					
BM	58	76.3	67	76.1	0.68
PBPC	15	19.7	15	17.0	
Cord	3	3.9	6	6.8	
CD34+ dose, $\times 10^6$/kg					
Mean ± s.d.	2.56 ± 1.44		2.89 ± 2.12		0.64
Median (range)	2.42 (0.05–6.20)		2.48 (0.05–11.55)		
Days until platelet engraftment, platelets >20 000 (n = *62 and 79*)					
Mean ± s.d.	26 ± 17		26 ± 17		0.91
Median (range)	21 (11–102)		20 (6–124)		
Readmission within 1 year of discharge	57	75.0	70	79.5	0.49
Total readmission days within 1 year of discharge					
Mean ± s.d.	32 ± 38		18 ± 20		0.09
Median (range)	20 (0–159)		12 (0–93)		
Relapse	23	30.3	28	31.8	—
100-Day mortality	13	17.1	16	18.2	0.86
Vital status: dead	54	71.1	47	53.4	—

Table 1. (Continued)

Variable	*No CP* (n = *76*)		*CP* (n = *88*)		P-*value*
	N	%	N	%	
Cause of death (n = *54 and 47*)					
Relapse	18	33.3	24	51.1	—
Acute GVHD	5	9.3	7	14.9	
Chronic GVHD	6	11.1	4	8.5	
Infection	9	16.7	7	14.9	
Pulmonary	10	18.5	3	6.4	
Other	6	11.1	2	4.3	
Worst episode of acute GVHD					
None	25	32.9	29	33.0	—
Grade 1–2	39	51.3	44	50.0	
Grade 3–4	12	15.8	15	17.0	
Worst episode of chronic GVHD					
None	45	59.2	48	54.5	—
Limited	10	13.2	18	20.5	
Extensive	21	27.6	22	25.0	
Duration of follow-up among patients who are still alive (n = *22 and 41*)					
Mean ± s.d.	42.0 ± 17.5		40.9 ± 15.7		0.76
Median (range)	42.9 (16.4–72.2)		41.2 (17.4–73.7)		

Abbreviations: CP = care-partner; HCT-CI = hematopoietic cell transplantation-specific co-morbidity index; MDS = myelodysplastic syndrome. [a]Significantly different between groups ($P \leqslant 0.05$).

Table 2. PACT scale ratings by CP status

PACT scale item	*No CP* (n = *76*) *Mean ± s.d.*	*CP* (n = *88*) *Mean ± s.d.*	P-*value*
PACT Q1. Family or support system stability ($n = 75, 88$)	4.0 ± 0.9	4.5 ± 0.7	<0.001[a]
PACT Q2. Family or support system availability ($n = 75, 88$)	3.7 ± 0.8	4.7 ± 0.6	<0.001[a]
PACT Q3. Psychopathology, stable personality factors ($n = 75, 88$)	4.0 ± 0.9	4.2 ± 0.9	0.05[a]
PACT Q4. Risk for psychopathology ($n = 74, 88$)	4.0 ± 0.9	4.3 ± 0.8	0.013[a]
PACT Q5. Healthy lifestyle, ability to sustain change in lifestyle ($n = 75, 88$)	4.2 ± 0.9	4.5 ± 0.9	0.007[a]
PACT Q6. Drug and alcohol use ($n = 74, 88$)	4.6 ± 0.7	4.7 ± 0.6	0.33
PACT Q7. Compliance with medications and medical advice ($n = 73, 88$)	4.4 ± 0.8	4.6 ± 0.7	0.06
PACT Q8. Understanding of transplant and follow-up: relevant knowledge and receptiveness to education ($n = 75, 87$)	3.8 ± 1.0	4.1 ± 0.9	0.025[a]

Abbreviations: CP = care-partner; PACT = psychosocial assessment of candidates for transplantation. [a]Significantly different between groups ($P \leqslant 0.05$).

visitation was 86% (range 11–100% of days). Duration and frequency were significantly correlated ($r = 0.512$; $P < 0.001$); CPs who visit more frequently also tend to stay longer each day. Duration > 3 h per day was associated with better patient survival ($P = 0.004$) and RFS ($P = 0.007$). Frequency of visitation > 75% associated with better survival ($P = 0.004$) and RFS ($P = 0.010$).

DISCUSSION

This prospective study validates that having an in-hospital lay CP significantly improves patient survival. Given that partnership may be a major source of positive interaction in hematopoietic cell transplantation[20] and that problematic support is prognostic of poor survival in autologous BMT,[21] not measuring patient perceptions of CP and family or other social support is a limitation of the present study.

Although having an in-hospital lay CP was associated with the PACT Scale items of family or support system availability and stability, these should not be viewed as equivalent. CP support is qualitatively different to support from family or other support systems; the CP is an intimate mediator,[22] coordinating patient-team-family member relationships during the in-patient phase of the transplant. Such coordination may, to some extent, account for better compliance with medications and medical advice and better understanding of transplant and follow-up.

That patient employment status was statistically significant in univariable, but not in the multivariable analysis, leads to speculation that this is a co-morbidity variable; patients who are employed versus receiving disability coming into transplant may enjoy better health. And, even though parental status was NS this variable may be a relevant risk factor because patients in the no CP group were found more likely to have children. Caution in interpretation is warranted as both patient groups were of similar age and only 2% of the CPs was adult children; while caring for dependent children may limit availability of a CP, having adult children is not necessarily of benefit for caregiving.

The study also redefines a consistent and vigilant CP in terms of optimal duration and frequency of in-hospital visits with respect to

Table 3. CP characteristics ($n = 88$)

Variable	N	%
Gender		
Female	60	68.2
Male	28	31.8
Age category (years)		
18–30	9	10.2
31–40	4	4.5
41–50	38	43.2
51–60	28	31.8
61–70	7	8.0
70+	2	2.3
CP lived with patient prior to admission		
Yes	77	87.5
No	11	12.5
CP relationship to patient		
Spouse	53	60.2
Parent	26	29.5
Significant other	5	5.7
Sibling	2	2.3
Child	2	2.3
Level of education		
<12th grade	3	3.4
High school or vocational training	36	40.9
Some college	22	25.0
College degree	27	30.7
Vocation		
Professional	34	38.6
Technical/Clerical	20	22.7
Laborer	12	13.6
Other	22	25.0
Employment Status		
Employed	58	65.9
Disabled	4	4.5
Other	26	29.5

Abbreviation: CP = care-partner.

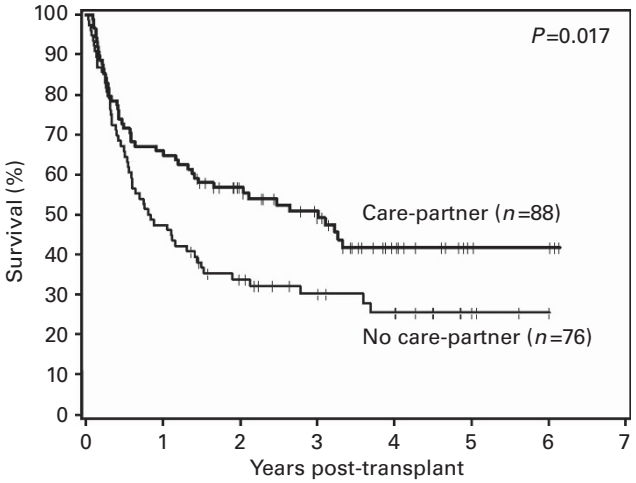

Figure 1. Patient survival by CP status.

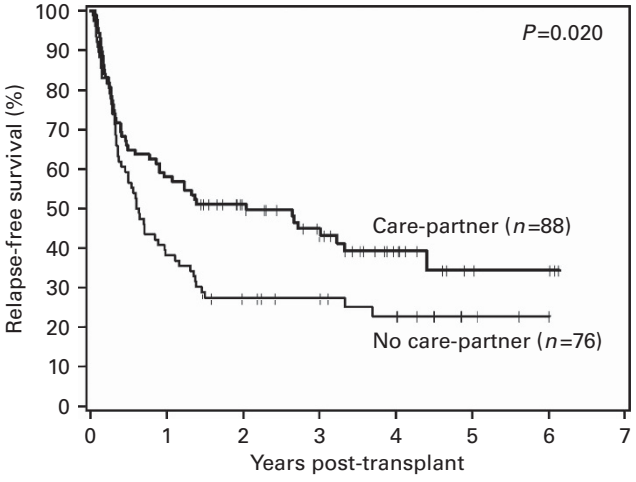

Figure 2. Patient RFS by CP Status.

survival. These data establish a zone of CP helpfulness that optimizes not only the quantity of CP participation behaviors, but likely the quality of CP involvement in the care-giving relationship as well. That is, the zone of helpfulness may represent levels of participation CPs and patients need in order to meaningfully confide and emotionally process feelings evoked by the transplant experience. That a CP who visits more frequently also tends to stay longer each day demonstrates their level of commitment and involvement in sharing the transplant experience.

Sharing the experience of allo BMT integrates patient and medical narratives, keeps the patient's mind and body connected, supports the will to push forward, and meaningfully places the transplant experience in the context of their lives. The literature on mind-body connections posits '…that a person can be well in his or her 'being'—in the deeper level of the self—while sick and impaired physically,[23] and that such self-perceived health is associated with better survival'.[24,25] BMT patients may rely upon their CP to go beyond the physical for their sense of well-being. As concluded in a medical journal editorial, '… it is clear that a confiding relationship necessarily activates the social brain and facilitates the physiology of hope'.[13]

The literature indicates that 'the influence of social relationships on risk for mortality is comparable with well-established risk factors for mortality',[26] and perceived positive social and familial support is associated with better survival in allogeneic BMT.[27–29] However, the literature also indicates that support from one partner may differ qualitatively and have more influence on survival than family or support systems,[10,18] a finding in this study. Support from social relationships may lack the emotional processing found in partnered relationships, such as CP and patient.

Furthermore, patients with a consistent CP during the critical hospitalization phase may be more likely to have a partnered relationship that extends beyond day 100. That long-term and non-relapse mortality was greater for those without an in-hospital CP, while 100-day mortality rates do not differ, suggests that there may be long-term positive effects from having an in-hospital CP. The level of commitment and involvement indicated by duration and frequency of CP in-hospital visits may continue beyond day 100; patients who had this level of CP support are not left alone to cope with medical complications or needs beyond day 100. This ongoing CP support may help decrease complications that are preventable and decrease the impact of treatment toxicities, thus improving long-term and non-relapse mortality rates.

To summarize, an in-hospital lay CP has a significant, positive influence on patient survival. How the science of caring translates to survival is beyond the scope of the present study. The authors are mindful that not having a consistent and vigilant lay CP may

Table 4. Identifying prognostic factors for survival and RFS: univariable analysis

Variable	*Survival*			*RFS*		
	HR	*95% CI*	P-*value*	*HR*	*95% CI*	P-*value*
Patient has a CP						
No/yes	1.61	1.09–2.38	0.018[a]	1.56	1.07–2.28	0.021[a]
Employment status						
Disabled/employed	1.60	1.05–2.44	0.030[a]	1.34	0.90–2.01	0.15
Other/employed	1.06	0.55–2.02	0.87	0.90	0.48–1.71	0.76
PACT Q2: family or support system availability						
Per 1 point increase	0.79	0.63–0.99	0.042[a]	0.78	0.63–0.97	0.026[a]
PACT Q8: understanding of transplant and follow-up						
Per 1 point increase	0.78	0.63–0.96	0.019[a]	0.80	0.66–0.97	0.024[a]
Co-morbidity index, HCT-CI						
Intermediate/low risk	1.09	0.66–1.79	0.74	1.10	0.69–1.76	0.68
High/low risk	1.76	1.10–2.81	0.019[a]	1.50	0.95–2.37	0.08
HLA matched						
No/yes	1.67	1.01–2.76	0.044[a]	1.63	1.00–2.65	0.05[a]
Source of hematopoietic cells						
PBPC/BM	1.51	0.94–2.42	0.09	1.45	0.92–2.30	0.11
Cord/BM	2.19	1.01–4.77	0.048[a]	2.03	0.94–4.41	0.07

Abbreviations: CI = confidence interval; CP = care-partner; HCT-CI = hematopoietic cell transplantation-specific co-morbidity index; HR = hazard ratio; PACT = psychosocial assessment of candidates for transplantation; RFS = relapse-free survival. [a]Significant ($P \leqslant 0.05$).

Table 5. Identifying prognostic factors for survival and RFS: multivariable analysis

Variable	*Survival*			*RFS*		
	HR	*95% CI*	P-*value*	*HR*	*95% CI*	P-*value*
Patient has a CP						
No/yes	1.60	1.07–2.40	0.022[a]	1.57	1.06–2.31	0.023[a]
PACT Q8: understanding of transplant and follow-up						
Per 1 point increase	0.78	0.63–0.96	0.019[a]	0.80	0.66–0.97	0.024[a]
Co-morbidity index, HCT-CI						
Intermediate/low risk	0.97	0.58–1.61	0.90	—	—	—
High/low risk	1.66	1.03–2.67	0.036[a]	—	—	—
HLA matched						
No/yes	1.94	1.15–3.27	0.013[a]	1.88	1.13–3.13	0.015[a]

Abbreviations: CI = confidence interval; CP = care-partner; HCT-CI = hematopoietic cell transplantation-specific co-morbidity index; HR = hazard ratio; PACT = psychosocial assessment of candidates for transplantation; RFS = relapse-free survival. [a]Significant ($P \leqslant 0.05$).

be related to pre-morbid patient characteristics and problematic dynamics within the patient's family.[30] Definitive interpretive statements regarding how CP status may reflect these risk factors, as well as socio-demographic differences in the patient population, remain a focus for future research.

Given that positive carryover effects post-transplant may exist for patients having an in-hospital lay CP, designing an ongoing CP support program that supports all lay CPs, outpatient as well as inpatient is warranted. Critical to designing a support program for in-hospital lay CPs are cut-points for optimum duration and frequency of in-hospital visits. In-hospital CPs need education pre-transplant as to how often to participate because creating the space for CP-patient involvement favorable to confiding and emotionally processing the transplant experience may contribute to a positive outcome. Intervention for patients without inpatient CP support is especially important with the goal of improving their survival rates. Future intervention based research could focus on whether survival for these patients could be improved by providing them with support groups, peer mentoring, counseling and other psychosocial supportive services. Also, the fact that both our earlier research on the PACT scale[31] and our present research reveal understanding of transplant and follow-up to be significantly associated with patient survival suggest the importance of education for outpatient CPs. CPs and patients lacking the shared in-hospital transplant experience would likely benefit from supportive education that nurtures understanding of transplant and the development of a new care-giving relationship, one that incorporates the realities of living with a transplant.

BMT team members are ultimately faced with the ethical concern of how to counsel a family before transplant about the importance of an in-hospital CP without family members feeling overly responsible for the survival of their loved one. Toward this end, operationally defining a consistent and vigilant CP and establishing a zone of helpfulness optimizing CP involvement is useful. Knowing the survival value of in-hospital lay CPs in allogeneic transplantation obliges the BMT team to intervene at a programmatic as well as the patient and family level; CPs are integral to the mosaic of care in BMT.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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