

QUALITY IMPROVEMENT

Characteristics of Distress and Support Group Participation in Caregivers of Older Allogeneic Hematopoietic Cell Transplantation Patients: A Single Institution Retrospective Review

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Authors' disclosures of conflicts of interest are found at the end of this article.

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Abstract

Older patients with hematologic malignancies are increasingly considered for allogeneic hematopoietic cell transplant (allo-HCT). However, older patients often have increased comorbidities and thus may require an increased level of post-transplant care. These factors can contribute to increased caregiver distress, which has been associated with worsened health outcomes for caregivers and patients. To examine predictors of caregiver distress and support group participation in caregivers of older allo-HCT patients, we retrospectively reviewed charts of 208 patients aged 60 and older who underwent their first allo-HCT at our institution from 2014 through 2016. We systematically characterized and identified the incidence of caregiver distress and attendance in a caregiver support group from the start of conditioning through 1 year post allo-HCT. Evidence of caregiver distress and support group participation was recorded by reviewing clinical and/or social work documentation. We found that 20 caregivers (10%) endorsed stress and 44 caregivers (21%) attended our support group at least once. A patient's prior history of psychiatric diagnosis ($p = .046$) or the use of potentially inappropriate medications for older adults ($p = .046$) was found to be associated with caregiver stress. Caregivers who were spouses or partners of patients ($p = .048$) or caregivers of married patients were more likely to attend the support group ($p = .007$). While limited by retrospective design and likely underreporting, this study

reveals factors associated with caregiver distress in the older allo-HCT caregiver population. This information can help providers identify caregivers at risk for distress and improve caregiver resources, which may improve both caregiver and patient outcomes.

Older adults represent a significant population of allogeneic hematopoietic cell transplant (allo-HCT) recipients; in 2018, 38% of allo-HCT recipients were 60 or older (D'Souza et al., 2020). Allo-HCT is a potentially curative therapy for hematologic malignancy, but one that comes with significant morbidity and mortality. Patients undergoing this treatment require substantial monitoring and support in the post-HCT period. Due to complex patient needs, HCT centers often require patients to stay close to the transplant center with an informal caregiver (usually a family member or friend who provides unpaid support) available 24/7 for at least the first 100 days post HCT. Caregiving challenges may be further augmented with increasing patient age. Older patients may have vulnerabilities, including medical comorbidities, cognitive and functional impairments, nutritional deficits, potentially inappropriate medication use, higher risk malignancy, and increased toxicities (Lin et al., 2020). Such vulnerabilities have the potential to require increased caregiver involvement and increase caregiver distress in this population.

Caregiver distress can be described as a state of psychological or emotional suffering, often including symptoms of anxiety and depression, as a result of caregiving. Beyond subjective distress symptoms, the chronic stress associated with caregiving can induce a physiologic response affecting neuroendocrine and emotional processes and potentially hypothalamic pituitary axis dysregulation (Bevans & Sternberg, 2012; Bevans et al., 2016). This stress can be linked to adverse health outcomes, including increased infection risk, slow wound healing, and increased proinflammatory states (Bevans & Sternberg, 2012).

Support groups allow people with similar challenges to gather and share their experiences and emotions in a safe, supportive environment. A meta-analysis by Chien and colleagues (2011) found that support groups improved outcomes such as depression, burden, and psychological well-being in caregivers of dementia patients. Similarly, caregivers of cancer patients who participated in support group

therapy reported improved quality of life compared with control group participants (Mahendran et al., 2017). A study of brain tumor patients and their caregivers attending support groups indicated that support group participants noted feelings of camaraderie and kinship among their peers; however, participants noted barriers to attendance such as logistics (childcare, transportation, etc.) and lack of reminders or invitations (Mallya et al., 2020). Overall, evidence suggests that support groups can provide a benefit to caregivers.

While there is a scarcity of literature on the benefits of support groups in caregivers of older allo-HCT patients specifically, the benefits of social support are well known. Social worker-led caregiver support groups are a cost-effective way to offer social support and attempt to mitigate caregiver distress. At Memorial Sloan Kettering Cancer Center (MSKCC), support groups are offered by social workers to caregivers of HCT patients, although caregiver attendance is variable.

Given the known challenges of caregiving for older adults and allo-HCT patients, we decided to retrospectively examine the prevalence of caregiver distress and caregiver support group participation in the older allo-HCT patient population. We further aimed to evaluate associations between pretransplant factors and caregiver distress or support group participation in this population. Further understanding of these characteristics may help clinicians better identify caregivers at risk of distress and increase access to the support group. Identifying at-risk caregivers and patterns in support group participation may reduce caregiver distress in caregivers of older adult patients undergoing allo-HCT and consequently improve both caregiver and patient health.

METHODS

Patient and Transplant Characteristics

This study included patients aged 60 years and older who underwent their first allo-HCT at our institution from 2014 to 2016. A waiver of authorization for this retrospective review was obtained from the Institutional Review and Privacy Board.

In a retrospective chart review process, two independent investigators (TAE and RJL) identified relevant social work, demographic, and caregiver data from the start of conditioning through 1 year post allo-HCT. Caregiver attendance at the institutional social worker-led caregiver support group on the HCT unit was captured by reviewing social work documentation of caregiver participation. Clinical documentation was reviewed to capture demographic information including patient age and gender, transplant conditioning intensity, graft information including source and degree of donor HLA match, graft-vs.-host disease (GVHD) prophylaxis regimen, underlying malignancy, performance status, cytomegalovirus (CMV) serostatus, comorbidity index (assessed by HCT-Comorbidity Index [HCT-CI] documentation), and Disease Risk Index (DRI). The revised DRI and HCT-CI were scored according to the published criteria (Armand et al., 2014; Sorror, 2013).

Additional documentation by physical therapy, occupational therapy, nutrition, nursing, and social work staff was reviewed to evaluate pretransplant baseline activities of daily living (ADL) and instrumental activities of daily living (IADL) impairments, nutritional status (as defined by weight loss of 10 pounds or greater in past 3 months), impaired cognition (as defined by Montreal Cognitive Assessment [MoCA] score), use of potentially inappropriate medications (PIM) prior to transplant as defined by the American Geriatrics Society Updated Beers Criteria (2015), patient ethnicity, patient marital status, patient history of psychiatric illness and psychiatry evaluation prior to transplant, level of pretransplant social support as documented by social work, and type of patient-caregiver relationship.

Social work and clinical documentation were reviewed for evidence of caregiver distress, as well as the clinical or social circumstances surrounding the distress. Caregiver distress was defined in this setting as any social work or clinical documentation of evidence of emotional distress in the setting of caregiving, which included such keywords as burnout, fatigue, burden, or difficulty coping. Social work notes were reviewed for documentation of caregiver participation in a weekly support group offered to caregivers of admitted transplant patients. In this analysis, caregiver support group

attendance was not considered an intervention, but was included to provide additional caregiver data. No standardized instruments were used given the retrospective nature of this study. All data were anonymized to protect the identities of the subjects involved.

Statistical Methods

The caregiver population was characterized using descriptive traits, including frequencies, medians, and ranges. Relationships between patient clinical, demographic, and caregiver characteristics with both caregiver distress and caregiver support group attendance were statistically evaluated using univariable logistic regression. Variables included: age, gender, marital/partnership status, race/ethnicity, Karnofsky Performance Scale (KPS), diagnosis, HCT-CI/age index, revised DRI, donor type, conditioning intensity, GVHD prophylaxis regimen, recipient CMV serostatus, geriatric variables of impairments in ADL and IADL, nutrition status, falls history, PIM use, patient history of psychiatric diagnosis, history of psychiatry evaluation pre-HCT, caregiver/patient relationship type, and pre-HCT level of social support.

RESULTS

Patient Demographics and Characteristics of Allogeneic HCT

Baseline characteristics of the study cohort ($N = 208$) are listed in Table 1. Forty-four percent of patients were female, and 93% were white. Seventy-seven percent of patients were married or partnered. The median age was 67, and ages ranged from 60 to 78.7 years. The cohort included a heterogeneous group of malignancies, with 70% being myeloid and 30% being lymphoid. With respect to overall comorbidity burden, 61% of patients had an HCT-CI score of 3 or greater. The KPS was below 90 in 51% of patients. Eighty-two percent of patients received peripheral blood stem cell grafts. A slight majority (55%) of the cohort received nonmyeloablative or reduced intensity conditioning regimens. Most patients (77%) had fully matched donors, and 72% of matched donors were unrelated. The majority (62%) of patients received an unmodified GVHD prophylaxis regimen, while the remainder of the cohort received modified regi-

Table 1. Patient Demographics and Clinical and Transplant Characteristics

Characteristic	N	n (%)
Sex	208	
Female		92 (44%)
Male		116 (56%)
Age, Mdn (%)	208	67 (4.1%)
Race/Ethnicity	208	
White		193 (93%)
Not White		15 (7.2%)
Marital status	208	
Married/Partnered		160 (77%)
Single/Divorced/Widowed		48 (23%)
Transplant diagnosis	208	
Lymphoid		63 (30%)
Myeloid		145 (70%)
Karnofsky Performance Score	207	
< 90		105 (51%)
≥ 90		102 (49%)
HCT-CI	208	
0-2		81 (39%)
≥ 3		127 (61%)
Disease Risk Index, Revised	208	
Low/Intermediate		145 (70%)
High/Very high		63 (30%)
Graft source	208	
Peripheral blood		170 (82%)
Bone marrow		29 (14%)
Cord		9 (4.3%)
Conditioning intensity	208	
Myeloablative		94 (45%)
NMA/RIC		114 (55%)
Donor type	208	
Matched related		45 (22%)
Cord blood		9 (4.3%)
Haploidentical		14 (6.7%)
Matched unrelated		115 (55%)
Mismatched (≤ 7/8) unrelated		25 (12%)
Recipient CMV status	208	
Negative		75 (36%)
Positive		133 (64%)

Table 1. Patient Demographics and Clinical and Transplant Characteristics (cont.)

Characteristic	N	n (%)
GVHD prophylaxis	208	
Unmodified		130 (62%)
Ex-vivo CD34+ selected		57 (27%)
Post-transplant cyclophosphamide		21 (10%)
Impaired ADL	208	
Impairment		12 (5.8%)
No impairment		196 (94%)
Impaired IADL	206	
Impairment		24 (12%)
No impairment		182 (88%)
Impaired cognition	174	
Impairment		65 (37%)
No impairment		109 (63%)
Polypharmacy	208	6.2 (3.8)
Potentially inappropriate medication use	208	
No potentially inappropriate meds		106 (51%)
Potentially inappropriate meds		102 (49%)
Depression	208	
No prior history		168 (81%)
Prior history		40 (19%)
Prior fall within 12 mo	208	
No prior falls		166 (80%)
Prior fall(s)		42 (20%)
Weight loss 10 lbs or more in 3 mo	208	
No weight loss		165 (79%)
Weight loss		43 (21%)
Caregiver relationship	208	
Spouse/partner		148 (71%)
Children		28 (13%)
Others, including multiple		32 (15%)
Pre-HCT psychiatry evaluation	203	
SW only		181 (89%)
SW + psych		22 (11%)

Note. ADL = activities of daily living; CMV = cytomegalovirus; GVHD = graft-vs.-host disease; HCT-CI = hematopoietic cell transplant-comorbidity index; IADL = instrumental activities of daily living; NMA = nonmyeloablative; RIC = reduced intensity conditioning; SW = social work.

Table 1. Patient Demographics and Clinical and Transplant Characteristics (cont.)

Characteristic	N	n (%)
Pre-HCT social support	203	
High		132 (65%)
Moderate		71 (35%)
Pre-HCT psychiatric diagnosis	208	
No		146 (70%)
Yes		62 (30%)

Note. ADL = activities of daily living; CMV = cytomegalovirus; GVHD = graft-vs.-host disease; HCT-CI = hematopoietic cell transplant-comorbidity index; IADL = instrumental activities of daily living; NMA = nonmyeloablative; RIC = reduced intensity conditioning; SW = social work.

mens such as ex vivo CD34+ selected cells or post-transplant cyclophosphamide.

Geriatric Impairments and Caregiver Characteristics

Table 1 also illustrates baseline geriatric impairments in patients and caregiver/psychosocial support details. The most common geriatric impairments were in domains of function, depression, mobility, cognition, nutrition, and medications, including 12% with impaired IADL, 19% with history of depression, 20% with prior fall within last year, 21% with significant weight loss (defined as 10 lbs or more over the past 3 months), and 49% with PIM use. Only 174 patients (84%) had pre-transplant MoCA performed, with 37% demonstrating impaired cognition (score < 26).

While most patients in the cohort had caregivers who were either a spouse or partner (71%), 13% of caregivers were children of the patient, and 15% of caregivers were categorized as multiple caregivers or “other,” which included siblings, friends, more distant family members, and hired caregivers. While 203 patients (98%) had a psychosocial assessment done prior to HCT, 89% of these patients had social work evaluations alone, and 11% of patients had evaluations by social work and psychiatry at our institution. Of the 203 patients who had social work assessments prior to transplant, 65% of these patient assessments indicated high social support, and 35% indicated moderate social support. Thirty percent of patients had a docu-

mented psychiatric history (primarily depression or anxiety) prior to transplant; these included patients with a remote history of psychiatric illness in addition to patients who continued active treatment and psychiatry follow-up.

Univariable Analysis of Caregiver Distress and Support

The univariable analyses are summarized in Table 2. The only variables significantly associated with reported caregiver distress are potentially inappropriate medication use and psychiatric history prior to HCT. Caregiver distress was associated with patient use of potentially inappropriate medications for older adults (odds ratio [OR], 2.65, confidence interval [CI] = 1.02–7.76, $p = .046$). Additionally, patient psychiatric history prior to HCT admission was associated with reported caregiver distress (OR, 2.62, CI = 1.02–6.73, $p = .046$). Of note, caregiver age was not significantly associated with caregiver distress (OR, 0.96, CI = 0.85–1.07, $p = .48$).

The variables significant for caregiver support group attendance were marital status and type of caregiver relationship; no other variables had a statistically significant relationship with caregiver support group attendance. Although there was significant overlap between married/partnered patients (77%) and patients whose caregivers were their partner/spouse (71%), not all married/partnered patients had their spouse/partner as a caregiver. Married or partnered patients were more likely than single, divorced, or widowed patients to have their caregivers attend the caregiver support group (OR, 0.27, CI = 0.08–0.73, $p = .007$). Similarly, the type of patient/caregiver relationship significantly influenced caregiver support group attendance. Support group attendance was significantly more likely in caregivers who were married to/partnered with patients, compared with caregivers who were children of patients (OR, 0.23, CI = 0.04–0.82, $p = .048$).

DISCUSSION

We examined the relationship between caregiver distress and support group participation among caregivers of older adults undergoing allo-HCT at a single institution. We further demonstrated a relationship between caregiver distress and po-

Table 2. Demographic, Clinical, and Transplant Characteristics Associated With Caregiver Distress and Caregiver Support

Characteristic	Caregiver distress			Caregiver support		
	OR	95% CI	p value	OR	95% CI	p value
Sex			.59			.62
Female	-	-		-	-	
Male	0.77	0.30-1.97		1.19	0.61-2.36	
Age, M (%)	0.96	0.85-1.07	.48	0.98	0.90-1.06	.65
Race/Ethnicity			.67			.11
White	-	-		-	-	
Not White	0.65	0.04-3.54		0.25	0.01-1.29	
Marital status			.35			.007
Married/Partnered	-	-		-	-	
Single/Divorced/Widowed	0.56	0.13-1.77		0.27	0.08-0.73	
Transplant diagnosis			.58			.38
Lymphoid	-	-		-	-	
Myeloid	1.34	0.49-4.27		1.39	0.67-3.08	
Karnofsky Performance Score			.95			.57
< 90	-	-		-	-	
≥ 90	1.03	0.41-2.63		0.82	0.42-1.60	
HCT-CI			.17			.45
0-2	-	-		-	-	
≥ 3	2.04	0.75-6.47		1.30	0.66-2.67	
Disease Risk Index, Revised			.33			.80
Low/Intermediate	-	-		-	-	
High/Very high	1.61	0.60-4.12		1.10	0.52-2.21	
Graft source			.40			.69
Peripheral blood	-	-		-	-	
Bone marrow	0.30	0.02-1.56		1.01	0.35-2.53	
Cord	1.06	0.06-6.25		1.93	0.39-7.70	
Conditioning intensity			.62			.47
Myeloablative	-	-		-	-	
NMA/RIC	1.26	0.50-3.36		0.78	0.40-1.53	
Donor type			.53			.57
Matched related	-	-		-	-	
Cord blood	1.75	0.08-15.8		3.25	0.57-16.4	
Haploidentical	1.08	0.05-9.26		1.77	0.33-7.96	
Matched unrelated	1.33	0.39-6.16		1.99	0.81-5.69	
Mismatched (≤ 7/8) unrelated	3.50	0.78-18.5		1.62	0.42-6.05	

Note. ADL = activities of daily living; CI = confidence interval; CMV = cytomegalovirus; GVHD = graft-vs.-host disease; HCT-CI = Hematopoietic Cell Transplant-Comorbidity Index; IADL = instrumental activities of daily living; NMA = nonmyeloablative; OR = odds ratio; RIC = reduced intensity conditioning; SW = social work.

Table 2. Demographic, Clinical, and Transplant Characteristics Associated With Caregiver Distress and Caregiver Support (cont.)

Characteristic	Caregiver distress			Caregiver support		
	OR	95% CI	p value	OR	95% CI	p value
Recipient CMV status			.70			.76
Negative	-	-		-	-	
Positive	0.83	0.33-2.21		1.12	0.56-2.29	
GVHD prophylaxis			.96			.27
Unmodified	-	-		-	-	
Ex-vivo CD34+ selected	1.16	0.38-3.15		1.82	0.86-3.77	
Post-transplant cyclophosphamide	1.04	0.15-4.20		1.45	0.44-4.15	
Impaired ADL			.11			.22
Impairment	-	-		-	-	
No impairment	0.28	0.08-1.37		3.09	0.58-57.3	
Impaired IADL			.63			> .99
Impairment	-	-		-	-	
No impairment	0.72	0.22-3.27		1.00	0.37-3.18	
Impaired cognition			.37			.17
Impairment	-	-		-	-	
No impairment	1.62	0.58-5.27		1.70	0.80-3.82	
Polypharmacy	1.08	0.96-1.21	.20	0.94	0.86-1.03	.23
Potentially inappropriate medication use			.046			.59
No potentially inappropriate meds	-	-		-	-	
Potentially inappropriate meds	2.65	1.02-7.76		0.83	0.42-1.62	
Depression			.079			.84
No prior history	-	-		-	-	
Prior history	2.53	0.89-6.68		0.92	0.37-2.08	
Prior fall within 12 mo			.27			.71
No prior falls	-	-		-	-	
Prior fall(s)	1.81	0.61-4.85		0.85	0.34-1.92	
Weight loss 10 lbs or more in 3 mo			.62			.23
No weight loss	-	-		-	-	
Weight loss	1.32	0.41-3.64		1.61	0.73-3.42	
Caregiver relationship			.98			.048
Spouse/partner	-	-		-	-	
Children	1.15	0.25-3.84		0.23	0.04-0.82	
Others, including multiple	0.99	0.22-3.28		0.56	0.18-1.44	

Note. ADL = activities of daily living; CI = confidence interval; CMV = cytomegalovirus; GVHD = graft-vs.-host disease; HCT-CI = Hematopoietic Cell Transplant-Comorbidity Index; IADL = instrumental activities of daily living; NMA = nonmyeloablative; OR = odds ratio; RIC = reduced intensity conditioning; SW = social work.

Table 2. Demographic, Clinical, and Transplant Characteristics Associated With Caregiver Distress and Caregiver Support (cont.)

Characteristic	Caregiver distress			Caregiver support		
	OR	95% CI	p value	OR	95% CI	p value
Pre-HCT psychiatry evaluation			.056			.90
SW only	-	-		-	-	
SW + psych	3.25	0.97-9.63		1.07	0.34-2.90	
Pre-HCT social support			.33			.27
High	-	-		-	-	
Moderate	1.60	0.61-4.06		0.66	0.31-1.36	
Pre-HCT psychiatric diagnosis			.046			.97
No	-	-		-	-	
Yes	2.62	1.02-6.73		0.98	0.46-2.01	

Note. ADL = activities of daily living; CI = confidence interval; CMV = cytomegalovirus; GVHD = graft-vs.-host disease; HCT-CI = Hematopoietic Cell Transplant-Comorbidity Index; IADL = instrumental activities of daily living; NMA = nonmyeloablative; OR = odds ratio; RIC = reduced intensity conditioning; SW = social work.

tentially inappropriate medication use, as well as prior patient history of psychiatric illness. We also observed a relationship between caregiver support group participation and patient marital status, and similarly observed an association between caregiver support group participation and patient/caregiver relationship type, specifically, patients married to/partnered with their caregivers.

Due to the complexity of care and time commitment required, caregivers of allogeneic HCT patients have unique burdens and may suffer from distress as they struggle to balance their caregiving responsibilities with their personal lives. Often, caregivers' needs are deprioritized, including nutrition, sleep, exercise, and leisure activities (Bevans & Sternberg, 2012). Caregivers of allo-HCT patients may need to clean and rearrange their homes, provide detailed medication management, monitor symptoms and vital signs, and provide transportation to the transplant center for frequent visits. Many caregivers feel inadequately trained to provide the complex care required after allo-HCT, including management of medications and monitoring of symptoms (Gemmill et al., 2011). Caregivers may also grapple with the sensitive nature of the cancer diagnosis and the conversations about disease-related or treatment-related mortality that may be part of an HCT patient's care. Providing emotional support to patients, especially related to discussions on end of life, is a

source of distress for caregivers (Applebaum et al., 2016). This distress may manifest in physiologic changes, as caregivers of HCT patients have reported symptoms including sleep disturbances and depression, and physical health effects such as hypothyroidism (Jamani et al., 2018). Among this patient/caregiver cohort, potentially inappropriate medication use and prior patient history of psychiatric illness may have contributed to the complexity of medical care and emotional support required of caregivers, consequently contributing to caregiver stress.

The relationship dynamic between caregivers and allo-HCT patients may influence the risk of caregiver stress, and consequently caregiver support group participation. Caregivers of adult HCT patients are commonly partners and spouses; spouses of cancer patients are an at-risk caregiving population and can experience distress at least as much as their sick partners (Bishop et al., 2007). Spousal caregivers of older patients are especially vulnerable, as they are likely to be older themselves and with increased comorbidities (Burton et al., 1997). They may face social support issues, including isolation and family tension, which have been identified as significant sources of burden for caregivers (Gemmill et al., 2011). Financial burden is also a potential contributor to caregiver stress; as most transplant centers require patients and caregivers to reside close to the transplant center

for at least 100 days post transplant, these requirements often result in caregivers having to relocate and take a leave of absence from work (Applebaum et al., 2016; Simoneau et al., 2013). The costs associated with decreased income, medical care, and lodging can cause further financial stress, which has been a reported source of caregiver burden (Adelman et al., 2014; Denzen et al., 2016). While there was no relationship identified between patient/caregiver relationship and caregiver stress, spousal/partnered caregivers may have been significantly more likely to seek support by participation in the caregiver support group offered, which may have helped reduce caregiver stress.

These findings could help clinicians identify caregivers at risk for distress in this patient population. For example, patients with a diagnosis of depression or anxiety prior to HCT may have their caregivers preemptively referred to our support group and more closely followed by social work for signs of distress. Additionally, clinicians could increase outreach for caregivers who were less likely to attend the support group, such as those who were not married or partnered with patients. These caregivers may have had less support group attendance because they were less aware of the group, or this caregiver demographic may find another form of social support more appealing than a support group. Overall, this information can help clinicians better identify and manage distress in caregivers of older allo-HCT patients.

By increasing caregiver support and improving resources in these at-risk groups, both patients and caregivers can benefit. With respect to caregivers, evidence suggests that caregiver distress can significantly affect caregiver physical and mental health; for example, sleep disorders and depression are more prevalent in HCT patient caregivers than in the general population (Jamani et al., 2018). Caregiver burden and distress can also affect patient outcomes. Among the general population, caregiver burden is associated with increased mortality and hospitalization in community-dwelling adults aged 65 and over (Kuzuya et al., 2011). Specifically among allo-HCT patients, caregiver support can positively influence patient survival (Foster et al., 2013). While this has not been examined among caregivers of older allo-HCT patients, it is possible that this population

is more vulnerable due to the complexity of care required from caregivers. Overall, identification of at-risk caregiver groups may help us to better support caregivers at risk of distress and strengthen the resources available to them.

One limitation of this study is the retrospective study design, which likely contributed to under-reported distress. Additionally, many patients had multiple caregivers involved with their care, so not all caregivers may have been included in this analysis. This study was also limited by its relatively small sample size of 208 patients. An additional limitation is the study duration of 1 year post transplant, as symptoms of caregiver distress such as depression, cognitive dysfunction, fatigue, sleep, and sexual problems can persist well beyond the first year (Bishop et al., 2007). Furthermore, this study did not have any objective tools or standardized assessments used to measure caregiver distress; distress was captured subjectively, and many cases of distress could have been missed in this review if they were not documented in the medical record.

Lastly, the relationship between caregiver distress and acute triggering events was not examined. During chart review, we observed that caregiver distress was reported in multiple settings, including early in transplant admission, during patient pain episodes, critical illness, disease relapse, or readmission for complications. Caregiver distress was also noted when caregivers reported documented health issues, difficulty coping with patient illness, or lack of social support. Further investigation of the temporal relationship between caregiver distress and acute triggering events, as well as the types of triggering events, would provide a more thorough understanding of caregiver distress in this population.

To expand upon these findings, future studies might increase the sample size, extend follow-up beyond a year post HCT, and include a control group of non-caregivers. These findings highlight a dearth of literature related to caregiver distress in this patient population and emphasize a need for prospective studies using validated tools to quantitate caregiver distress, as well as studies examining whether caregiver support group participation has a mitigating effect on caregiver distress. Future studies might also further evaluate the re-

relationship between caregiver distress and patient outcomes after transplant to assess the impact of caregiver distress on patient health.

IMPLICATIONS FOR THE ADVANCED PRACTICE PROVIDER

At MSKCC, advanced practice providers (APPs) are involved in the care of allo-HCT patients throughout their course, including the pretransplant period, hospitalization for transplant and possible complications, posttransplant follow-up, and survivorship. Consequently, APPs caring for HCT patients have many opportunities to identify patient/caregiver dyads at risk of caregiver stress.

The role of the APP involves strong collaboration with patients, their caregivers, and the interdisciplinary team involved in patient care. In this role, APPs may identify patients with factors associated with caregiver distress, such as PIM use or psychiatric history. Advanced practice providers can support these patients and their caregivers by being mindful of these risk factors as they provide clinical care. For example, adjusting patients' medications (if clinically indicated), providing targeted psychiatric assessments, or referring these caregivers for additional psychosocial support may be beneficial. While social workers are an established, integral part of the HCT team, APPs and other clinicians on the HCT team can increase collaboration with social work to ensure caregivers with clinical risk factors of distress are followed more closely. By identifying caregivers at risk of distress and offering interventions such as caregiver support group participation, clinicians may contribute to reducing caregiver distress and its potential effects on caregiver and patient health. ●

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Disclosure

Dr. Perales reports honoraria from Abbvie, Astellas, Bristol-Myers Squibb, Celgene, Equilium, Incyte, Karyopharm, Kite/Gilead, Merck, Miltenyi Biotec, MorphoSys, Novartis, Nektar Therapeutics, Omeros, Takeda, VectivBio AG, and Vor Biopharma. He serves on DSMBs for Cidara Therapeutics, Medigene, Sellas Life Sciences, and Servier, and the scientific advisory board of NexImmune. He has ownership interests in NexImmune and Omeros. He has received research support for clinical trials from Incyte, Kite/Gilead, Miltenyi Biotec, and Novartis. He serves in a volunteer capacity as a member of the Board of Directors of the American Society for Transplantation and Cellular Therapy (ASTCT) and Be The Match (National Marrow Donor Program, NMDP), as well as on the CIBMTR Cellular Immunotherapy Data Resource (CIDR) Executive Committee. Dr. Giralt serves on the scientific advisory board of Actinium, Celgene, Bristol-Myers Squibb, Sanofi, Amgen, Pfizer, GlaxoSmithKline, JAZZ, Janssen, and Omeros. He reports research consultancy for Kite. He has received research support for clinical trials from Actinium, Bristol-Myers Squibb, Celgene, Pfizer, Takeda, Janssen, Amgen, and Sanofi. Dr. Jakubowski reports ownership interest in Novartis. The other authors have no conflicts of interest to disclose.

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