Published in final edited form as:

Psychooncology. 2013 September ; 22(9): 2064–2070. doi:10.1002/pon.3259.

Elevated Peri-transplant Distress in Caregivers of Allogeneic Blood or Marrow Transplant Patients

Teresa L. Simoneau, Ph.D.[1], **Susan K. Mikulich-Gilbertson, Ph.D.**[2], **Crystal Natvig**[2], **Kristin Kilbourn, Ph.D.**[3], **Janet Spradley, LCSW**[1], **Rachel Grzywa-Cobb**[2], **Samuel Philips**[2], **Peter McSweeney, M.D.**[4], and **Mark L. Laudenslager, Ph.D.**[2]

[1]Presbyterian/St. Luke's Medical Center, Denver, Colorado

[2]University of Colorado at Denver Anschutz Medical Campus, Department of Psychiatry, Aurora, CO 80045

[3]University of Colorado Denver, Department of Psychology, Denver, CO

[4]Colorado Blood Cancer Institute, Denver, CO

Abstract

PURPOSE—A full-time 24/7 caregiver is required for 100 days or longer following an allogeneic blood or marrow transplant during which time caregivers have multiple demands. Although distress in caregivers is documented, generalization is limited by small sample sizes, restricted range of assessments, and lack of information as to which caregivers may be more vulnerable to distress. The purpose of this study was to describe the peri-transplant psychological status of a sample of caregivers of allogeneic transplant patients.

METHODS—We assessed caregiver mood, stress, burden, and sleep using valid self-report measures in 109 caregivers of allogeneic transplant patients prior to stem cell transplantation. Caregivers' scores were compared to norms or established cut-off scores for behavioral measures. Additionally, demographic characteristics such as age and sex were tested as predictors of distress.

RESULTS—Caregivers showed significant levels of anxiety, stress, intrusion and avoidance behaviors, and poor sleep at the start of transplant compared to established norms. Younger caregivers were more distressed than older caregivers. There were no differences in levels of distress between male and female caregivers.

CONCLUSION—The peri-transplant period is a time of heightened anxiety and distress for caregivers of allogeneic transplant patients. This study indicates that caregivers would benefit from support programs in the peri-transplant period. Recommendations for types of support that may be helpful to caregivers are provided but additional research is needed to validate that these programs would help caregivers providing care to patients receiving an allogeneic transplant in the peri-transplant period.

Corresponding author: Teresa Simoneau, Ph.D., Presbyterian/St. Luke's Medical Center, 1721 E. 19th Ave., Suite 200, Denver, CO 80218; 720-754-4850 (o); 720-754-4989 (fax); teri.simoneau@healthonecares.com..

Author conflicts: none.

Previous presentation: This study, using a smaller sample size, was presented as a paper at the American Psychosocial Oncology Society 7th Annual meeting and was published as an abstract: Simoneau TL, Mikulich-Gilbertson SK, Kilbourn K, Gryzwa R, Natvig C, Spradley J, Laudenslager ML, Caregivers of Allogeneic Transplant Patients: Pre-transplant Distress. *Psycho-Oncology*, 19 (Suppl. 1), S6, 2010.

Keywords

Cancer; oncology; caregiver; allogeneic transplant; stress; distress

---

Allogeneic stem cell transplantation is a common form of treatment for many types of blood cancers and requires active caregiver involvement for 100 days or longer [1]. The stress of caregiving starts before transplantation when families are preparing for the adversities of the transplant process. Caregivers are often involved in patients' treatment prior to transplantation since most caregivers are patients' immediate family members. As the start of transplant nears, the realities of the decision to proceed to transplant and associated risks for morbidity and mortality become increasingly concrete to the patient and caregiver. Although there is potential for significant improvement in the patients' disease status following transplant, there remains a high level of risk with the transplant procedure. Understanding caregiver adjustment to these peri-transplant stressors is important to identify support needs and develop interventions to help caregivers meet the caregiving challenge.

Caregivers of cancer patients face considerable risk regarding their own well-being. The burden of caregiving can have a significant impact on emotional, physical and social functioning [2-7], as well as immune and neuroendocrine processes [8, 9]. The patient and caregiver are closely connected in their experiences of dealing with the cancer; patient physical and psychological well-being is related to caregiver emotional and psychological well-being [10, 11]. From a systems perspective, this relationship would be bidirectional. Thus, caring for the caregiver is important for the health of the caregiver as well as the health of the patient.

Despite the critical role of caregivers, only limited research has focused on the caregiver experience and even fewer studies have focused on the caregiver during the allogeneic peri-transplant period. When allogeneic transplant patients and caregivers (n=40 and n=39, respectively) were compared on their pre-transplant psychosocial and psychological functioning, patients and caregivers reported significant distress prior to transplant [12]. Relatives of autologous and allogeneic transplant recipients reported stress significantly above the norm on the General Health Questionnaire, with stress greatest before and immediately following transplant [10]. Caregivers experienced greater anxiety and depression prior to transplant than five and 20 days post-transplant [13]. In a large study of autologous transplant caregivers (n=102), caregivers reported low levels of fatigue yet moderate levels of anxiety prior to transplant compared to population norms [14].

These studies suggest distress experienced by transplant caregivers is especially acute in the period preceding and immediately following transplantation of stem cells, i.e., the peri-transplant period. However, studies are limited by small sample sizes, restrictions in outcomes assessed, and heterogeneous patient groups consisting of both autologous and allogeneic transplant recipients or only autologous patient groups who present different caregiver challenges than allogeneic caregivers.

The purpose of this study was to describe the peri-transplant psychological status in a sample of caregivers of allogeneic transplant patients using measures of mood, perceived stress, sleep, and caregiving burden while determining if demographic or patient illness characteristics prior to transplant predicted levels of caregiver distress. We predicted that caregiver sex, age and patient status would contribute to overall peri-transplant caregiver distress. We hypothesized that female caregivers and younger caregivers would experience more distress than male or older caregivers.

Patients and Methods

Sample

Participants were caregivers of patients preparing for an allogeneic stem cell transplant for a hematological malignancy. Caregivers were defined as family members or friends who would be assuming the primary caregiver role (i.e., greater than 50%) for the patient during the post-transplant 100 day period. Transplant caregivers were recruited from the Rocky Mountain Blood and Marrow Transplant Program in Denver, Colorado between November 2008 and November 2011 as part of a larger intervention study assessing the efficacy of a caregiver stress management intervention on behavioral and physiological measures. Eligibility criteria included: 1) primary caregiver for the transplant patient for at least 50% of the time during the first 100 days post-transplant, 2) able to speak and read English, 3) 18 years or older, and 4) have access to a telephone. Exclusion criteria included: 1) a history of a psychiatric disorder in the past 18 months unrelated to the patient’s illness, 2) a serious medical condition likely to influence immune or neuroendocrine parameters measured in the larger parent study, 3) alcohol consumption greater than 1 drink/day, or 4) taking steroid medications. In addition to recruiting caregivers, we obtained informed consent from patients for collecting behavioral data and transplant-related medical information.

A staff member introduced the study to transplant candidates and their caregivers during the mandatory pre-transplant screening. If caregivers were interested in participating, an appointment was made to explain the study in detail and obtain informed consent. A total of 206 caregivers were approached and asked to participate of which 179 met eligibility criteria. Of those eligible, 119 caregiver/patient dyads consented to participate (66%). Primary reasons for refusal included lack of interest (38%) or feeling too overwhelmed to take on the additional tasks required of study participation (37%). Of the 119 who consented, 109 had complete data on all baseline outcome measures and were used for the present analyses. The Colorado Multiple Institutional Review Board (COMIRB) approved this study.

Behavioral Assessments

Commonly used instruments with high internal reliability and validity were completed by each subject to assess affective state (overall mood, depression and anxiety), perceived stress, caregiving burden, and general health. Questionnaires were provided to caregivers at the consent meeting. The day of consent was based on days relative to the day of transplant, which was treated as day 0. Most consents were obtained prior to transplant (M = −1.70 days before transplant; SD = 10.53 days). Participants indicated that they typically completed this battery in less than 45 minutes and generally reported no burden. Patients completed a general health questionnaire at the same time the caregivers completed their questionnaires. Questionnaires anchored the behavioral items on the past month. Thus the baseline assessments reported in this study generally reflect symptoms of distress in the month leading up to transplant, including the time immediately prior to transplant when patients received their conditioning regime consisting of chemotherapy or chemotherapy plus radiation.

Affective State Measures

Profile of Mood States (POMS)—The 65 item POMS, which is a list of adjectives describing a variety of moods scored on a 5 point Likert scale [15], was administered. It has six subscales (Tension, Anger, Vigor, Fatigue, Confusion, and Depression) and a summary total mood disturbance score (TMD) score. Internal consistency reliabilities are at .84 or above and test-retest reliability ranges from .65 to .74 [15]. Normative data are available for a general nonclinical population [16].

Center for Epidemiologic Studies – Depression (CES-D)—The CES-D is a commonly used depression scale consisting of 20-items with scores ranging from 0-60. Test-retest validity ranges from .51 to .67 over 2-8 weeks with an internal validity of .85 for a normal population [17]. Scores of 16 and above are viewed as reflecting significant depressive symptomatology [17].

State-Trait Anxiety Inventory (STAI)—The STAI [18] is a 40 item scale that asks subjects to rate how they feel “right now” (state; STAI-S) and how they “generally” feel (trait; STAI-T) on a 4 point Likert scale. Internal consistency ranges from .89 to .92 and test-retest correlations ranged from .73 to .86 [18]. The STAI has been used to effectively assess trait anxiety in caregiver populations [19, 20] and has established norms.

Stress measures

Perceived Stress Scale (PSS)—The 14 item PSS measures the degree to which subjects feel their lives are unpredictable, uncontrollable and overwhelming during the past month on a 5 point Likert scale [21]. The shorter 10-item scale was validated in 2,387 respondents across demographic characteristics with superior psychometric properties (reliability alpha of 0.84) [22]. Normative data from a general population sample are available [23].

Impact of Events Scale (IES)—The 15 item IES [24], scored on a 5 point Likert Scale, measures intrusion or avoidance symptoms around a specific event. For this study, the IES was anchored to the events and experiences of being a caregiver for the transplant recipient. Internal consistency was .78 and .82 for intrusion and avoidance, respectively. Test-retest reliability was .87 [24]. Scores over 20 indicate significant levels of PTS-like symptoms.

Burden Measure

Caregiver Reaction Assessment (CRA)—The CRA [25], which includes 24 items scored on a 5 point Likert scale covering domains of self-esteem, family support, finances, schedule, and health, was selected as a superior measure of caregiver burden [26]. It has excellent test-retest reliability of .9 and responsiveness to change of .81 [25] as well as normative data for a cancer caregiver population [27].

Health Measures

The Short Form (SF-36) Health Survey - Version 2.0 [28]—Caregivers and patients completed the 36-item scale indicating limitations in several domains. It has well-established norms and the scale is highly reliable (> .85) [29-31]. Caregiver scores on the physical health summary scale (SF-36 Physical) [32] were treated as an outcome variable; scores on the mental health subscales were not included in our analyses due to overlap with many of the items on the other affective state assessment measures. Patient scores on the mental health summary scale (SF-36 Mental) and physical health summary scale (SF-36 Physical) were used to assess relationships to caregiver behavioral measures.

Pittsburgh Sleep Quality Index (PSQI)—The PSQI [33-35] is a measure of sleep quality that provides sleep latency, sleep efficiency and sleep duration. It has acceptable reliability and validity with diagnostic sensitivity of 89.6% and specificity of 86.5% [33, 34]. Scores ≥ 5 indicate sleep difficulty.

Demographic Measure

Caregivers reported demographic information including age, sex, income, education level, relationship to the patient, caregiving hours, employment status, health behaviors (diet, exercise, alcohol and tobacco use, and physician visits), and medications.

Statistical Analyses

Data was entered and analyzed in SPSS version 19. Outcomes included caregiver scores on the POMS-TMD, CES-D, STAI-State, PSS, IES, CRA, PSQI and SF-36 Physical. Distributional characteristics of the outcome measures were examined and found to be approximately normal, with the exception of the caregiver SF-36 Physical summary scale. Pearson correlations were computed to assess inter-relationships among outcome variables except for caregiver SF-36 Physical, for which Spearman’s rank-order correlations were conducted due to non-normality of the data. A principal component analysis (PCA) was conducted to extract the first principal component from the 5 affective state and stress variables (POMS-TMD, CES-D, STAI-State, PSS and IES) to create a new “composite distress” score labeled Caregiver Distress (CG-Distress). To create an overall indicator of caregiver behavioral health capturing distress, sleep, caregiver burden, and physical health components, scores for CG-Distress, PSQI, CRA, and SF-36 Physical (inverted so that higher scores indicated worse health as on the other outcomes) were standardized (i.e. z-transformed) and summed to produce a variable labeled Caregiver Wellbeing (CG-Wellbeing).

Independent samples t-tests assessed whether caregiver behavioral health outcomes differed according to: 1) when baseline assessments occurred (i.e., before or after day of transplant [D = 0]), 2) sex, 3) duration of patient’s illness (less than 6 months or 6 months and greater since diagnosis), and 4) distance they lived from the transplant clinic (less than 45 miles or 45 miles and greater). The 45 mile radius was seen as significant because patients living outside this distance from the transplant clinic were required to relocate to Denver and live in temporary housing during the 100 day post-transplant period. Pearson’s correlations assessed the relationship between caregiver outcomes and caregiver age as well as patients’ scores on the SF-36 Mental and Physical summary scales. For caregiver SF-36 Physical summary score, the nonparametric equivalent analyses (i.e. Mann-Whitney U tests and Spearman’s rank-order correlations) assessed relationships with predictor variables.

The caregiver group consisted mainly of spousal caregivers and those who self-identified as being in a committed relationship with the patient (n=82), with parent caregivers representing the second largest group (n=16). To assess whether the heterogeneity of the caregiver group impacted the analyses, all analyses were conducted for the whole sample and in the subset of 82 spousal/partner caregivers. Results of the full sample and the subsample were similar so analyses are only reported for the full sample.

Results

Caregiver Demographics

The demographic characteristics of the participants are shown in Table 1 including patient illness variables. Most patients were being treated for leukemia (52%) and there was a large range in the duration of illness (1 - 195 months). Caregivers were predominately Caucasian females who were well-educated and middle-to upper-class.

Pre-transplant Caregiver Distress

Table 2 shows mean values and standard deviations for behavioral measures at the peri-transplant assessment period for caregivers as well as established cutoff values or population norms and the number (percent) of caregivers who either exceed the cut-off or were outside the population mean by +/− 1 SD. Many caregivers scored higher than normative samples on the POMS-TMD (67%), STAI-S (68%) and the PSS (65%). Most caregivers also scored well above established cutoffs for the IES (91%). Almost half of the caregivers scored above the cutoff for depression on the CES-D (45%). All caregivers scored higher than the established cutoff for sleep difficulties on the PSQI.

Most of the behavioral measures were highly correlated (Table 3). Furthermore, the summary principle components caregiver distress score (CG-Distress) was highly correlated with all of the caregiver behavioral measures except for the SF-36 Physical summary score. The summary principle components caregiver well-being score (CG-Wellbeing) was highly correlated with all of the caregiver behavioral measures.

Risk Factors for Pre-transplant Caregiver Distress

We used independent samples t-tests and Mann-Whitney U tests (for SF-36 Physical summary scores) to evaluate differences in caregiver behavioral outcomes depending on a number of predictor variables. Because some caregivers completed baseline assessment measures for the study after the day of transplant (D=0), we evaluated whether those caregivers were different in their level of distress than caregivers who were assessed before D=0. The overall mean for the day of the baseline assessment was -1.7 (SD=10.53) days before D=0. There was no significant difference between those caregivers who were assessed prior to D=0 (n=58) and those assessed after D=0 (n=51) in any of the caregiver behavioral measures. There were also no significant differences in caregiver behavioral measures between those whose patient's diagnosis was less than 6 months ago (n=37) and those whose patient's diagnosis was greater than 6 months ago (n=70), or between male (n=25) and female caregivers (n=84). For caregivers living closer to the transplant clinic (n=55) compared to those living farther away (n=53), there was a trend (U=1149; p<.058) for them to have a slightly higher (i.e. healthier) SF-36 Physical summary score (mean rank = 60.1 and 48.7, respectively); no other outcomes were related to clinic proximity.

Significant correlations were found between caregiver age and scores on the PSS (r=-.39, p <.0005), CRA (r=-.34, p <.0005), IES (r=-.23, p=.018), CES-D (r=.33, p=.001), POMS-TMD (r=-.37, p <.0005), STAI-S (r=-.30, p=.002), CG-Distress (r= -.38, p <.0005), and CG-Wellbeing (r= -.28,p=.003); that is, younger caregiver age was associated with greater distress. The patient SF-36 Mental summary score was significantly correlated with caregiver PSS (r=-.32, p<.002), CES-D (r=-.20, p<.048), and CG-Distress (r=-.24, p< .017) indicating that poorer patient mental health was associated with greater caregiver distress. The patient SF-36 Physical summary score was not correlated with any caregiver outcomes.

Discussion

Caregivers of allogeneic transplant patients reported significant levels of peri-transplant distress. Anxiety and stress levels for many caregivers exceeded population norms, and intrusive thoughts, avoidant behavior, and sleep difficulties were above clinically significant cutoff scores. Reports of sleep problems in caregivers of cancer patients are prevalent in the literature [36-38]. Alteration in the sleep-wake cycle can influence caregiver mood, affect, and physiological functioning. Caregivers reported high levels of distress and poor sleep regardless of whether their loved one was recently diagnosed with cancer or whether they had been dealing with their illness for a long time. Importantly, these baseline measures largely overlapped with the time leading up to transplant before the caregivers fully began the more demanding tasks of caring for the patient during transplant.

Younger caregivers were more distressed than older caregivers, which is consistent with other studies that have found younger age to be a risk factor for greater caregiver distress [39-41]. From a developmental perspective, caregivers in their 20's and early 30's are establishing themselves in careers and beginning a family. These life tasks are complicated by the demands of caregiving and add to an already challenging schedule. Younger caregivers may lack the life experience and skills to cope with demands of providing care to someone with a life-threatening illness.

There was no sex difference noted in the levels of caregiver distress in this study: both male and female caregivers scored similarly on behavioral measures. Other studies have shown mixed results regarding the impact of sex on caregiving stress. Palliative care and hospice studies have generally failed to show an effect of sex on psychosocial distress in caregivers [11]. However other studies show greater distress in female caregivers compared to male caregivers [39, 42-44]. This demographic characteristic needs more in-depth study as a potential predictor in caregiver research.

Caregivers of patients with poorer mental health functioning tended to be more distressed than those of patients with better mental health functioning. A relationship between *patient* physical functioning and caregiver well-being was not observed. Mutuality has been observed in other studies where the patient's physical or mental state is related to caregiver physical or mental well-being [11]. Caregivers are often the main emotional support for transplant patients and they are likely to be impacted by the patients' experiences. While caregiver support is very important for the well-being and overall outcome of the patient's transplant [10, 45], it comes at a high cost to the caregiver. Caregiver stress is related to changes in physiological functioning [46-49]. Assessing interventions that lessen the impact of caregiving on well-being of caregivers is an important area to address in future research.

The allogeneic peri-transplant period is a time of heightened anxiety and distress as well as poor sleep for caregivers of transplant patients suggesting the need for intervention and support in this population. Caregivers are often present for the initial consultation between the patient and transplant physician and caregivers frequently accompany patients to their pre-transplant assessments. Assessment of caregiver well-being should occur during these meetings to identify baseline distress and need for intervention, such as depression, anxiety, or sleep difficulties. With a paucity of research on transplant caregivers, the types of support and interventions that might be helpful to caregivers during transplant remain untested. However, given the universality of sleep difficulties in this caregiver population, the importance of good sleep hygiene should be stressed with caregivers and evidence-based treatments for sleep offered. Behavioral [50, 51], cognitive behavioral [52-55], and exercise interventions [56] are efficacious interventions for improving sleep quality in cancer patients but studies assessing the efficacy of sleep interventions in cancer caregivers are warranted.

Caregivers of transplant patients commonly report specific concerns, stresses and symptoms including fatigue, fear of the unknown, high levels of uncertainty, and desire for information [13, 57, 58]. We developed an 8-session caregiver stress management intervention which is currently being assessed via a randomized controlled trial by our group. Topics covered by the intervention include: 1) stress management and coping skills training, 2) strategies for maintaining energy and stamina, 3) dealing with uncertainty, 4) managing changing relationships, and 5) enhancing support (Simoneau et al, in review). Our stress management program was set up as an individual intervention which allowed for flexibility in scheduling since time management is a primary issue with transplant caregivers. These and other intervention trials are needed to enhance knowledge of strategies that may help address caregiver concerns.

Strengths of this study include recruiting a large allogeneic caregiver population and assessing a broad range of outcome variables salient to the caregiver population. A limitation is the lack of diversity in the study caregiver population. Most caregivers were married, Caucasian females, who were well-educated and of middle-to upper-class. Females are over-represented in caregiver populations [5, 6, 39]. In our study, the percentage of male caregivers recruited from those approached (58%) was lower than the percentage of female caregivers recruited from those approached (69%) but this difference was not significant. Male patients outnumbered female patients by 2:1 resulting in a preponderance of female caregivers since most were spouses. The low number of non-Caucasian participants in our study is representative of the population in the mountain states region from which patients were referred to the transplant program where the study was conducted. The recruitment rate for non-Caucasian caregivers (55%) was similar to that of the Caucasian caregivers (54%). Future research should over-recruit a more diverse group of caregivers to determine if findings from this study generalize to caregivers of different racial or ethnic groups.

Implications

This study highlights the high level of distress experienced by caregivers of allogeneic transplant patients in the peri–transplant period. A caregiver is a requirement for patients to proceed to transplant, yet little is known of these caregivers' needs and experiences as they take on the responsibility of the patients' care. Addressing caregiver well-being and distress through well-designed interventions provided as an adjunct to the transplant process is needed.

Acknowledgments

The authors are particularly grateful to the caregivers who not only gave their time to the care of their patients but who also accepted the added burden of participating in this study. The authors are thankful to Susan Lutgendorf, Ph.D. for her important contributions in the development of this study, and Africa Armendariz, Robert Hill, and Maribel Perea for their expert contributions to the execution of this study. This study was registered at ClinicalTrials.gov: Identifier: NCT00833898.

Funded by Grant No. 3R01CA126971 from the National Institutes of Health

References

1. Blume, KG.; Amylon, MD. The evaluation and counseling of candidates for hematopoietic cell transplantation. In: Blume, KG.; Forman, SJ.; Appelbaum, FR., editors. Thomas' Hematopoietic Cell Transplantation. 3rd ed. Blackwell Publishing; Massachusetts: 2004. p. 449-462.
2. Bevans M, Sternberg EM. Caregiving burden, stress, and health effects among family caregivers of adult cancer patients. JAMA. 2012; 307:398–403. [PubMed: 22274687]
3. Haley WE, LaMonde LA, Han B, Narramore S, Schonwetter R. Family caregiving in hospice: Effects on psychological and health functioning among spousal caregivers of hospice patients with lung cancer or dementia. Hosp J. 2001; 15:1–18. [PubMed: 11876341]
4. Zi J, Zoller B, Sundquist K, Sundquist J. Increased risks of coronary heart disease and stroke among spousal caregivers of cancer patients. Circulation. 2012; 125:1742–1747. [PubMed: 22415143]
5. Pinquart M, Sorensen S. Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. Psychol Aging. 2003; 18:250–267. [PubMed: 12825775]
6. Stenberg U, Ruland C, Miaskowski C. Review of the literature on the effects of caring for a patient with cancer. Psychooncology. 2010; 19:1013–1025. [PubMed: 20014159]
7. Vitaliano PP, Zhang J, Scanlan JM. Is caregiving hazardous to one's physical health? A meta-analysis. Psychol Bull. 2003; 129:946–972. [PubMed: 14599289]
8. Futterman AD, Wellisch DK, Zighelboim J, et al. Psychological and immunological reactions of family members to patients undergoing bone marrow transplantation. Psychosom Med. 1996; 58:472–80. [PubMed: 8902898]
9. Rohleder N, Marin TJ, Ma R, Miller GE. Biologic cost of caring for a cancer patient: Dysregulation of pro- and anti-inflammatory signaling pathways. J Clin Oncol. 2009; 27:2909–2915. [PubMed: 19433690]

10. Keogh F, O'Riordan J, McNamara C, et al. Psychosocial adaptation of patients and families following bone marrow transplantation: a prospective, longitudinal study. Bone Marrow Transplant. 1998; 22:9905–911.
11. Williams AL, McCorkle R. Cancer family caregivers during the palliative, hospice, and bereavement phases: A review of the descriptive psychosocial literature. Palliat Support Care. 2011; 9:315–25. [PubMed: 21838952]
12. Siston AK, List MA, Daugherty CK, et al. Psychosocial adjustment of patients and caregivers prior to allogeneic bone marrow transplantation. Bone Marrow Transplant. 2001; 27:1181–1188. [PubMed: 11551029]
13. Foxall M, Gaston-Johansson F. Burden and health outcomes of family caregivers of hospitalized bone marrow transplant patients. J Adv Nurs. 1996; 24:915–923. [PubMed: 8933250]
14. Gaston-Johansson F, Lachica E, Fall-Dickson J, et al. Psychological distress, fatigue, burden of care, and quality of life in primary caregivers of patients with breast cancer undergoing autologous bone marrow transplantation. Oncol Nurs Forum. 2004; 31:1161–1169. [PubMed: 15547639]
15. McNair, DM.; Loor, M.; Droppleman, LF. ETS manual for the Profile of Mood States. Educational and Industrial Testing Services; San Diego: 1992.
16. Nyenhuis DL, Yamamoto C, Luchetta T, Terrien A, Parmentier A. Adult and geriatric normative data and validation of the Profile of Mood States. J Clin Psychol. 1999; 55:79–86. [PubMed: 10100834]
17. Radloff LS. The CES-D Scale: A self report depression scale for research in the general population. Appl Psych Meas. 1977; 1:385–401.
18. Spielberger, CD.; Gorsuch, RL.; Lushene, R., et al. Manual for the State-Trait Anxiety Inventory. Consulting Psychologists Press, Inc; California: 1983.
19. Claar RL, Parekh PI, Palmer SM, et al. Emotional distress and quality of life in caregivers of patients awaiting lung transplant. J Psychosom Res. 2005; 59:1–6. [PubMed: 16126089]
20. Raveis VH, Karus D, Pretter S. Correlates of anxiety among adult daughter caregivers to a parent with cancer. J Psychosoc Oncol. 2006; 17:1–26.
21. Cohen S, Kamarck T, Mermelstein R. A global measure of perceived stress. J Health Soc Behav. 1983; 24:385–96. [PubMed: 6668417]
22. Cohen, S.; Kessler, RC.; Gordon, LU. Measuring stress: A guide for health and social scientists. Oxford University Press; New York: 1995.
23. Cohen, S.; Williamson, GM. Perceived stress in a probability sample of the United States. In: Spacapan, S.; Oskamp, S., editors. The Social Psychology of Health. Sage Publishing; California: 1988. p. 31-67.
24. Horowitz M, Wilner N, Alvarez W. Impact of Event Scale: A measure of subjective stress. Psychosom Med. 1979; 41:209–18. [PubMed: 472086]
25. Given CW, Given B, Stommel M, et al. The Caregiver Reaction Assessment (CRA) for caregivers to persons with chronic physical and mental impairments. Res Nurs Health. 1992; 15:271–83. [PubMed: 1386680]
26. Deeken JF, Taylor KL, Mangan P, et al. Care for the caregivers: A review of self-report instruments developed to measure the burden, needs, and quality of life of informal caregivers. J Pain Symptom Manage. 2003; 26:922–53. [PubMed: 14527761]
27. Grov EK, Fosså SD, Tønnessen A, Dahl AA. The caregiver reaction assessment: psychometrics, and temporal stability in primary caregivers of Norwegian cancer patients in late palliative phase. Psycho-Oncology. 2006; 15:517–527. [PubMed: 16189843]
28. Ware, JE.; Kosinski, M.; Dewey, JE. How to Score Version 2 of the SF-36® Health Survey. Quality Metric Incorporated; Rhode Island: 2000.
29. Beusterien KM, Steinwald B, Ware JE Jr. Usefulness of the SF-36 health survey in measuring health outcomes in the depressed elderly. J Geriatr Psychiatry Neurol. 1996; 9:13–21. [PubMed: 8679058]
30. Ware JE. SF-36 health survey update. Spine. 2000; 25:3130–3139. [PubMed: 11124729]
31. Ware JE Jr. Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. Med Care. 1992; 30:473–83. [PubMed: 1593914]

32. Ware, JE., Jr; Kosinski, M.; Keller, S. SF-36 physical and mental health summary scales: A user's manual. 2nd Ed. Health Institute, New England Medical Center; Massachusetts: 1994.

33. Buysse DJ, Reynolds CF 3rd, Monk TH, et al. The Pittsburgh Sleep Quality Index: A new instrument for psychiatric practice and research. Psychiatry Res. 1989; 28:193–213. [PubMed: 2748771]

34. Buysse DJ, Reynolds CF 3rd, Monk TH, et al. Quantification of subjective sleep quality in healthy elderly men and women using the Pittsburgh Sleep Quality Index (PSQI). Sleep. 1991; 14:331–8. [PubMed: 1947597]

35. Hall M, Baum A, Buysse DJ, et al. Sleep as a mediator of the stress-immune relationship. Psychosom Med. 1998; 60:48–51. [PubMed: 9492239]

36. Berger A, Parker K, Young-McCaughan S, et al. Sleep-wake disturbances in people with cancer and their caregivers: State of the science. Oncol Nurs Forum. 2005; 32:E98–126. [PubMed: 16270104]

37. Carter PA. Caregivers' descriptions of sleep changes and depressive symptoms. Oncol Nurs Forum. 2002; 29:1277–83. [PubMed: 12370697]

38. Carter PA, Chang BL. Sleep and depression in cancer caregivers. Cancer Nurs. 2000; 23:410–415. [PubMed: 11128119]

39. Kim Y, Carver CS. Recognizing the value and needs of the caregiver in oncology. Curr Opin Support Palliat Care. 2012; 6:1–9. [PubMed: 22246043]

40. Kim Y, Spillers RL. Quality of life of family caregivers at 2 years after a relative's cancer diagnosis. Psychooncology. 2010; 19:431–440. [PubMed: 19399773]

41. Nijboer C, Tempelaar R, Sanderman R, et al. Cancer and caregiving: The impact on the caregiver's health. Psychooncology. 1998; 7:3–13. [PubMed: 9516646]

42. Gaugler JE, Hanna N, Linder J, et al. Cancer caregiving and subjective stress: A multi-site, multi-dimensional analysis. Psychooncology. 2005; 14:771–785. [PubMed: 15750995]

43. Hagedoorn M, Sanderman R, Bolks HN, et al. Distress in couples coping with cancer: A meta-analysis and critical review of role and gender effects. Psychol Bull. 2008; 34:1–30. [PubMed: 18193993]

44. Sugiura K, Ito M, Kutsumi M, et al. Gender differences in spousal caregiving in Japan. J Gerontol B Psychol Sci Soc Sci. 2009; 64:147–56. [PubMed: 19176486]

45. Bolwell BJ, Foster L, McLellan L, et al. The presence of a caregiver is a powerful prognostic variable of survival following allogeneic bone marrow transplantation. Blood. 2001; 98:845.

46. Kiecolt-Glaser JK, Preacher KJ, Maccallum RC, et al. Chronic stress and age-related increases in the proinflammatory cytokine IL-6. Proc Natl Acad Sci U S A. 2003; 100:9090–5. [PubMed: 12840146]

47. Kiecolt-Glaser JK, Gouin JP, Hantsoo L. Close relationships, inflammation, and health. Neurosci Biobehav Rev. 2010; 35:33–8. [PubMed: 19751761]

48. Maier SF. Bi-directional immune-brain communication: Implications for understanding stress, pain, and cognition. Brain Behav Immun. 2003; 17:69–85. [PubMed: 12676570]

49. von Känel R, Dimsdale JE, Mills PJ, et al. Effect of alzheimer caregiving stress and age on frailty markers interleukin-6, C-reactive protein, and D-dimer. J Gerontol A Biol Sci Med Sci. 2006; 61:963–9. [PubMed: 16960028]

50. Berger AM, Kuhn BR, Farr LA, et al. Behavioral therapy intervention trial to improve sleep quality and cancer-related fatigue. Psychooncology. 2009; 18:634–646. [PubMed: 19090531]

51. Berger AM, Kuhn BR, Farr LA, et al. One-year outcomes of a behavioral therapy intervention trial on sleep quality and cancer-related fatigue. J Clin Oncol. 2009; 27:6033–6040. [PubMed: 19884558]

52. Morin CM, Vallières A, Guay B, et al. Cognitive behavioral therapy, singly and combined with medication, for persistent insomnia: A randomized controlled trial. JAMA. 2009; 301:2005–2015. [PubMed: 19454639]

53. Savard J, Simard S, Ivers H, Morin CM. Randomized study on the efficacy of cognitive-behavioral therapy for insomnia secondary to breast cancer, Part I: Sleep and psychological effects. J Clin Oncol. 2005; 23:6083–6096. [PubMed: 16135475]

54. Savard J, Simard S, Ivers H, Morin CM. Randomized study on the efficacy of cognitive-behavioral therapy for insomnia secondary to breast cancer, Part II: Immunologic effects. J Clin Oncol. 2005; 23:6097–6106. [PubMed: 16135476]
55. Woodward SC. Cognitive-behavioral therapy for insomnia for patients with cancer. Clin J Oncol Nurs. 2011; 15:E42–E52. [PubMed: 21810565]
56. Tang MF, Liou TH, Lin CC. Improving sleep quality for cancer patients: Benefits of a home-based exercise intervention. Support Care Cancer. 2010; 18:1329–39. [PubMed: 19834744]
57. Boyle D, Blodgett L, Gnesdiloff S, et al. Caregiver quality of life after autologous bone marrow transplantation. Cancer Nursing. 2000; 23:193–203. [PubMed: 10851770]
58. Zabora JR, Smith ED, Baker F, Wingard JR, Curbow B. The family: The other side of bone marrow transplantation. J Psychosoc Onc. 1992; 10:35–46.

Table 1

Patient and Caregiver characteristics (N=109)

Variable	**n (%)**	**Mean (SD)** **Range**
Patient		
Age (years)		49.83 (12.6)
		20-72
Female	33 (30)	
Diagnosis		
Leukemia	57 (52)	
Lymphoma	23 (21)	
MDS/MPS	19 (17)	
Other (MM, SAA)	10 (9)	
Duration of Illness (months)		28.1 (37.6)
		1-195
Caregiver		
Age (years)		52.2 (11.3)
		21-80
Female	84 (77)	
Ethnicity		
Caucasian	103 (94)	
Education		
College or above	60 (55)	
Relationship to patient		
Spouse/partner	81 (75)	
Parent	16 (15)	
Other 12 (10)		
Annual income		
< $25,000	17 (16)	
$25,000-$44,999	23 (22)	
$45,000-$64,999	20 (19)	
>$65,000+	45 (43)	
Employment Status	Before Caregiving n (%)	During Caregiving n (%)
Full-time	55 (51)	29 (27)
Part-time	19 (17)	14 (13)
Unemployed	13 (12)	16 (15)
On leave	2 (2)	27 (25)
Retired	18 (16)	19 (18)

Note. MDS=myelodysplastic syndrome; MPS=myeloproliferative syndrome; MM=multiple myeloma; SAA=severe aplastic anemia.

Table 2

Descriptive statistics of caregiver behavioral measures (N=109) at baseline compared to normative samples

Assessment Measure	Caregiver Mean (SD)	Population mean (SD) or cutoff	N (%) Caregivers ≥ Cutoff or > population Mean by 1 SD
POMS TMD	63.4 (36.5)	12.7 (29.6)	N=73 (67%)
CES-D	15.2 (9.6)	depression cutoff ≥	16 N=49 (45%)
STAI-S	40.7 (10.9)	35.96 (1.1)	N=74 (67.9%)
SF-36-Physical	54.6 (8.1)	50 (10)	N=0
PSS	23.4 (8.4)	19.1 (7.1)	N=71 (65.1%)
CRA	65.1 (8.9)	67.2	N=41 (37.6%)
IES	30.5 (8.0)	PTSD cutoff ≥19	N=99 (90.8%)
PSQI	11.5 (2.7)	Sleep difficulty cutoff ≥5	N=109 (100%)

Table 3

Correlations among Behavioral Outcome Measures (N=109)

Behavioral Measure	POMS TMD	CES-D	STAI-S	SF-36 Physical	PSS Global	CRA	IES	PSQI	Cg Distress	Cg Wellbeing
POMS TMD	1	.805[**]	.796[**]	−.201[*]	.817[**]	.521[**]	.499[**]	.542[**]	.933[**]	.792[**]
CES-D		1	.687[**]	−.202[*]	.778[**]	.512[**]	.492[**]	.488[**]	.894[**]	.748[**]
STAI-S			1	−.059	.711[**]	.362[**]	.502[**]	.463[**]	.875[**]	.645[**]
SF-36-Phys				1	−.132	−.293[*]	.011	−.159	−.139	−.483[**]
PSS Global					1	.477[**]	.413[**]	.430[**]	.888[**]	.687[**]
CRA						1	.405[*]	.360[**]	.534[**]	.761[**]
IES							1	.407[**]	.648[**]	.535[**]
PSQI								1	.547[**]	.732[**]
Cg Distress									1	.804[**]
Cg Wellbeing										1

Note. Cg Distress = factor analysis score of POMS, CES-D, STAI-S, PSS, IES; Cg Wellbeing = z score of Cg Distress + SF-36-Physical (inverted scores) + PSQI + CRA. Pearson correlations coefficients are reported for all outcomes except for associations with SF-36 Physical, which was non-normally distributed and for which Spearman’s rho are reported.

[*] p < .05 (2-tailed).

[**] p < .001 (2-tailed).