The Relationship of Health Behaviors with Sleep and Fatigue in Transplant Caregivers

Alyson Ross, PhD, RN[1],*, **Li Yang, MS**[1], **Stephen D. Klagholz, BS**[1], **Leslie Wehrlen, RN, MS, OCN®**[1], and **Margaret F. Bevans, PhD, RN, AOCN®, FAAN**[1]

[1]National Institutes of Health Clinical Center, Nursing Department, Bethesda, MD

Abstract

Objective—The burden and psychological impact of providing care to a loved one with cancer is significant and associated with a number of problems including sleep disturbance and fatigue. While engaging in healthy behaviors such as proper nutrition, exercise and stress reduction may improve sleep and fatigue, few studies have focused on this relationship. The objective of this study is to examine the relationship of health behaviors with sleep quality and fatigue in transplant caregivers.

Methods—Data were analyzed from a cross-sectional survey of 78 caregivers of patients undergoing allogeneic hematopoietic stem cell transplantation. Measures included: Health-Promoting Lifestyle Profile II (HPLP-II), Brief Symptom Inventory (Distress), Caregiver Reaction Assessment (Caregiver Burden), Pittsburgh Sleep Quality Index, and the Multidimensional Fatigue Symptom Inventory Short-Form.

Results—Controlling for age, gender, BMI, burden and distress, health behaviors predicted sleep quality (B=−.408, *p*=.021) and fatigue (B=−.966, *p<.001*). Stress management (B=−.450, *p*=.001), nutrition (B=−.249, *p*=.048), and interpersonal relationships (B=−.319, *p*=.049) were the HPLP-II subscales that significantly predicted sleep quality; nearly every HPLP-II subscale predicted fatigue.

Conclusions—Despite the burden and distress associated with caregiving, engaging in healthy behaviors may help to improve sleep and fatigue in transplant caregivers.

Keywords

Cancer; Oncology; Caregiver; Health Behaviors; Sleep; Fatigue

Background

Allogeneic hematopoietic stem cell transplantation (HSCT) involves the infusion of hematopoietic stem cells from healthy donors into patients with a variety of ailments, although it is most commonly used in hematologic malignancies such as leukemia and lymphoma [1]. While potentially curative, allogeneic HSCT is fraught with potential

*Corresponding author: Alyson Ross, PhD, RN, National Institutes of Health Clinical Center, Nursing Department, 10 Center Dr. Room 2B07, Bethesda, MD 20892, (301) 451-8338, rossac@cc.nih.gov.

complications including organ dysfunction, infection, and graft versus host disease (GVHD) [2]. Because the risk of morbidity and mortality remains high after the HSCT procedure, patients and a caregiver are required to remain close to the transplant center for approximately 100 days. Caregivers are critical partners during the acute phase of transplantation and remain necessary after those 100 days, as long-term consequences of HSCT that require caregiver assistance are common in up to 25% of HSCT survivors [3].

A number of research studies have examined the burden and psychological impact of cancer caregiving [4]. Levels of psychological distress experienced by caregivers are comparable or worse than those reported by their respective cancer patients and/or healthy controls [5]. Additionally, caregivers often prioritize their patient's needs over their own [6], and they adjust their lifestyles to accommodate the care recipient's needs including: reducing physical activity, decreasing leisure activity, and modifying relationships with friends and family [4]. In a comprehensive review of the literature involving 164 research studies examining emotional and physical impact of caring for individuals with cancer, the researchers identified more than 200 problems associated with cancer caregiving and found that problems with sleep and fatigue accounted for more than half of the physical health issues reported by the caregivers [7].

Sleep problems, particularly in caregivers of individuals with dementia, are well documented [8]. In dementia caregivers, distress predicts poor sleep, and poor sleep predicts several mental and physical health outcomes, including markers of cardiovascular disease risk [9]. In a review of 17 studies examining sleep in cancer caregivers, at least 40% of caregivers reported one or more sleep problems including short sleep duration, nocturnal awakenings, and daytime dysfunction [10]. Poor sleep quality contributes to psychological and physiological symptoms in cancer caregivers including: depression, anger, muscle tension, sympathetic arousal, cognitive disorganization, cardiopulmonary arousal, as well as neurological, gastrointestinal, and upper respiratory symptoms [11]. Lee et al (2008) found a strong relationship between levels of burden and sleep disturbance in 176 family caregivers of individuals with advanced cancer [12].

Because sleep disturbances are a concern for cancer caregivers, it is not surprising that fatigue is an issue as well. A literature review of 11 studies found that most cancer caregivers report moderate levels of fatigue [13]. Fatigue in cancer caregivers can mean more than simply feeling tired, as Cho et al. found depression positively correlated with fatigue [14].

A body of evidence is accumulating that cancer caregiving is both stressful and burdensome [4], and there is evidence linking the distress and burden of cancer caregiving to sleep disturbance and fatigue [10, 13]. Less clear is whether these symptoms directly result from the burden of caregiving, or whether the lifestyle adjustments, specifically a decrease in healthy behaviors such as exercise and stress reduction, may result in symptoms such as sleep problems and fatigue [15]. In caregivers of ovarian cancer patients, the majority reported at least one negative health change after their loved one's diagnosis, including decreased physical activity (42%) and weight gain (35%) [16]. In a population-based study, caregivers had higher odds of smoking and consuming fast food and high sugar drinks than

non-caregivers, even when controlling for psychological distress and demographic factors [17]. Using the Health-Promoting Lifestyle Profile II (HPLP-II) to examine health behaviors in a sample of 72 elderly female caregivers, Lee et al. (2009) found that caregivers reported higher scores for the subscales of cultivating interpersonal relationships (talking and sharing) and spiritual growth (reflection, prayer) than they did for the subscales of physical activity and stress management [18]. The authors concluded that caregivers may favor those health behaviors that provide caregivers with emotional strength without requiring time away from the patient.

This study is guided by a conceptual model by Vitaliano to explain how the impact of caregiving can lead to impairment in caregivers [19]. In this model, unique characteristics of the individual such as demographics and demands of caregiving (caregiver burden), along with psychosocial and behavioral factors (distress and health behaviors) as well as physiological aspects (age, BMI) contribute to the development of impairments such as sleep disturbance and fatigue.

Eating healthy food, exercising, and participating in stress reduction activities may help improve symptoms such as sleep and fatigue in cancer caregivers. Yet, while burden and distress are associated with worsened sleep quality and fatigue in caregivers, the role health behaviors play in the development of these symptoms is less clear. The purpose of this study is to examine the interrelationships between burden, distress, and health behaviors with sleep quality and fatigue. The primary aim is to examine whether, when controlling for the effects of distress and burden, health behaviors improve sleep quality and fatigue in HSCT caregivers.

Methods

Participants and Setting

This study utilized a single-group, cross-sectional design to analyze previously unpublished data from a clinical trial examining a problem-solving intervention for caregivers of HSCT patients [20]. Approval was obtained from the National Heart, Lung, and Blood Institute (NHLBI) Institutional Review Board. Subjects were included who were: 18+ years of age; a caregiver of a first-time allogeneic HSCT recipient; and English speaking. Subjects were from October 2008 through September 2010. Because many HSCT patients have multiple caregivers and no patient data is used in the analyses, more than one caregiver per patient was allowed to participate.

Data used in this analysis were collected before the start of the problem solving intervention, just prior to hospital discharge following HSCT. This time point was chosen for this analysis because it captures the time period when the caregivers were assuming full-time care for the HSCT recipient, a time when the distress and burden of caregiving, as well as problems with sleep and fatigue, likely would be high.

Measures

The following demographic data were collected: age, gender, race and ethnicity, education, relationship to caregiver, and patient diagnosis and treatment characteristics.

Health-Promoting Lifestyle Profile II (HPLP-II)—The HPLP-II is a self-administered 52-item instrument that measures the frequency of self-reported healthy behaviors using a 4-point Likert scale within six domains of a health promoting lifestyle [21]. The HPLP-II's six subscales capture behaviors that foster the development of physical, social, emotional, and psychological resources and strengths within each health-promoting domain: spiritual growth (reflection, prayer), interpersonal relations (confiding in others, sharing feelings), nutrition, physical activity, health responsibility (monitoring one's own health, seeking preventive health services), and stress management. Scores range from 52 to 208, with higher scores indicating more frequent engagement in health behaviors. Factor analysis confirmed a six-dimensional structure by convergence with the Personal Lifestyle Questionnaire (r = .678, p <.05), and criterion validity was completed using perceived health status (r = .269, p <.05) and quality of life (r = .491, p <.05) [21]. Cronbach's alpha reliability of the total HPLP-II in this study was .96, and subscale reliability ranged from .85–88.

Brief Symptom Inventory-18 (BSI-18)—The BSI-18 is an 18-item self-report measure of psychological distress [22]. Items are rated on a 5-point Likert scale, with higher scores indicative of higher levels of distress. Raw scores can be converted into t-scores that can be used to identify clinically significant levels of distress, with a GSI t-score 63 or a t-score 63 on two or more subscales indicative of significant distress [23]. In testing the construct validity of the measure, the BSI-18 correlated well with the Symptom Checklist-90[24]. Internal consistency in this study was .89.

Caregiver Reaction Assessment (CRA)—The CRA is a multidimensional assessment of burden and assesses positive and negative aspects of caregiving using 24-items and a 5-point Likert scale. The CRA includes five subscales: disrupted schedule, financial problems, lack of family support, health problems, impact of caregiving on self-esteem. The CRA has been validated in a caregivers from a number of patient populations, and construct validity was supported and it performed reliably well in a multicenter study involving cancer caregivers [25]. The sum of all subscales, reversing the esteem subscale, was used to create a total score. A higher total score indicates greater burden on the caregiver. Cronbach's alpha reliability in this study was .81.

Pittsburgh Sleep Quality Index (PSQI)—The PSQI is an 18 item self-report measure of subjective sleep quality during the past month [26]. The measure uses a 4-point Likert scale to measure sleep problems. There are seven components (sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medications, and daytime dysfunction) that are summed to produce a global score ranging from 0–21; higher scores indicate more sleep disturbance or worse sleep quality. There is strong support for the psychometric properties of the PSQI in a number of healthy and diseased populations [27]. A global PSQI score >5 is indicative of poor sleep quality [26]. Cronbach's alpha reliability in this study was .69.

Multidimensional Fatigue Symptom Inventory-Short Form (MFSI-SF)—The 30-item MFSI-SF uses a 5-point Likert scale to assess fatigue within the past week in the

following subscales: general, physical, vigor, emotional, and mental fatigue [28]. Higher scores are indicative of higher levels of the concept. Total score of the MFSI-SF is calculated by adding the sums of the subscales, with the vigor score reversed. Although originally created for use with cancer patients, the measure has been used in over 70 studies in a variety of healthy and diseased populations [28, 29]; The MFSI-SF performs well in psychometric testing, correlating well with a number of validated fatigue measures [29]. Cronbach's alpha reliability in this study was .79.

Statistical Analyses

All data analyses were done using IBM SPSS 20®. Frequency and percentages were used to describe categorical demographic and clinical characteristics. Mean and standard deviation were used for age, psychological, and behavioral measurements. Internal consistencies were measured using Cronbach's alpha coefficients. All demographic variables were examined using bivariate analyses as potential confounding variables, although none were found to be significantly related to the outcome variables. Bivariate correlations between continuous variables were assessed by Spearman's rho correlations. Group differences were tested using T-tests and one way analysis of variance (ANOVA) for normally distributed data and Mann-Whitney U and Kruskal-Wallis tests for ordinal or non-normal data.

Conceptually important variables (burden, distress, age, BMI and health behaviors) as well as gender, known to be related to sleep and fatigue, were put in the final multiple linear regression models on the two primary outcomes, total scores of sleep quality and fatigue. Total scores for both sleep quality and fatigue were square root transformed for the regression analyses to meet the normality assumption. Multicollinearity was checked by tolerance, VIF, and condition index. Post-hoc exploratory models using each individual subscale of the HPLP-II and the MFSI-SF were performed when the primary models were significant. Separate regression analyses were used to examine relationships between each subscale of the HPLP-II with total scores of sleep quality and fatigue, as well as to analyze the relationship between total HPLP-II scores with each subscale of fatigue. For all analyses, a p-value <.05 was considered significant.

Results

Sample Characteristics

One hundred eighty three caregiver subjects were screened for participation in the parent study, and 78 (43%) were eligible, completed questionnaires, and are included in these analyses (Figure 1). Demographic characteristics of the study participants are shown in Table 1. The majority of subjects were over age 50 (M=52.4±12.8), female (70.5%), non-Hispanic white (74.4%), and married (87.2%). Most attended some college (38.5%) or had a college degree (43.6%). Almost half (47.4%) were married to or partnered with the patient, while the remainder were parents (28.2%), other family members (16.7%), or friends (7.7%) of the adult patient. The majority of caregivers were overweight or obese (n=49; 63.6%), and 60.3% (n=47) reported at least one chronic health condition. Only two (2.6%) reported taking medications for sleep.

Nearly three quarters of the patients were being treated for cancer (n = 42; 73.7%), namely Lymphoma or Multiple Myeloma (n=29; 50.9%) and leukemia (n = 13; 22.8%); the remaining patients had non-malignant diseases such as sickle cell disease (n=8; 14.0%), myelodysplastic syndrome (n=3; 5.3%), and others (n=4; 7.0%). Most of the patients (n=50; 87.7%) were undergoing reduced intensity transplant procedures using peripheral blood (n=56; 98.2%).

Descriptive statistics for burden, distress, sleep quality, fatigue and health behaviors are shown in Table 2. The majority of subjects (n=50; 65.8%) reported a PSQI total score >5, indicative of poor sleep quality. Nearly 8% of subjects had BSI scores that were indicative of clinically significant distress. Physical activity was scored the lowest of all of the health behavior subscales, with the subscales of interpersonal relationships and spiritual growth scoring the highest.

Sleep Quality

The final model predicting sleep quality is shown in Table 3. In the final model, after controlling for the effects of age, gender, BMI, burden, and distress, the HPLP-II total score (B=−.408, p=.021) remained a negative predictor of the total PSQI score. When examining the contribution of the individual subscales of the HPLP-II on total PSQI scores and controlling for age, gender, BMI, distress and burden, stress management (B=−.450, p=.001), nutrition (B=−.249, p=.048), and interpersonal relationships (B=−.319, p=.049) significantly predicted PSQI scores.

Fatigue

The final model predicting fatigue is shown in Table 3. Controlling for age, gender, BMI, burden, and distress, health behaviors (B=−.966, p<.001) was a predictor of total fatigue scores. With the exception of spiritual growth (B=−.402, p=.084), all of the subscales of the HPLP-II were negative predictors of total fatigue scores when controlling for the effects of age, gender, BMI, burden, and distress, including health responsibility (B=−.425, p=.041), nutrition (B=−.429, p=.024), physical activity (B=−.637, p<.001), interpersonal relationships (B=−.736, p=.003), and stress management (B=−.746, p=.001). When exploring the relationship between the HPLP-II total score and the individual subscales of the MFSI-SF, the HPLP-II was a significant predictor of one of the five subscales, vigor (B=5.836, p<.001), when controlling for the effects of age, gender, BMI, burden, and distress.

Conclusions

Caregivers in this study were distressed, with nearly 10% exhibiting clinically significant levels of distress. Levels of psychological distress were comparable to those found in caregivers of persons with traumatic brain injury and higher than those found in maternal caregivers of children with eosinophilic gastrointestinal disorders [30, 31]. As in the study by Lee et al. (2009), the health behaviors practiced most frequently in this sample of caregivers were cultivating interpersonal relationships and spiritual growth [18]. The health behavior practiced least frequently in this study was physical activity, followed by stress management and health responsibility. This strengthens the argument that caregivers may

avoid physical activity, stress management, and health responsibility because of the time these activities require away from the care recipient. Creative thinking and research are needed to evaluate innovative ways to assist caregivers to increase levels of physical activity and reduce stress without having to physically leave the patient.

Sleep problems were an issue for these caregivers. Reported levels of sleep quality were worse in this population than those found in caregivers of patients with Alzheimer's and Parkinson's disease [32], but better than baseline levels of caregivers of individuals with advanced stage cancer [33]. It should be noted that the majority of caregivers was overweight or obese and had at least one chronic health condition. Both obesity and chronic health conditions could play a role in sleep quality. Because sleep was problematic in more than two thirds of the caregivers, it is somewhat surprising that fewer than 3% took any medications for sleep. While sleep medications are often prescribed for transplant patients [34], health care providers may not routinely be inquiring about the sleep quality of caregivers. Caregivers frequently put the needs of the patient above their own and may not be asking their own health care practitioners for help. Burden and distress both contributed to worsening quality of sleep, but individuals who practiced more healthy behaviors reported better sleep quality. Specific health behaviors may contribute to problems with sleep more than others, as nutrition, stress management, and interpersonal relationships all favorably predicted of sleep quality. However, the relationship between nutrition and interpersonal relationships with sleep quality should be interpreted with caution because of the threat of multiple comparisons. Stress management was more strongly associated with sleep quality than the other health behaviors, underscoring the importance of including a stress reduction component in interventions designed to improve sleep in caregivers. Research is needed to examine the comparative effectiveness of different stress management techniques such as meditation, yoga, progressive relaxation, and biofeedback on sleep in cancer caregivers.

Fatigue levels in this population were lower than those found in Alzheimer's caregivers [35]but higher than those found in a sample of healthy volunteers [36]. Nearly every subcategory of health behaviors including nutrition, health responsibility, physical activity, interpersonal relations, and stress management was related to lower levels of fatigue. It is particularly interesting that the subscale of fatigue that changed the most as healthy behaviors increased was vigor. Individuals who engaged in more healthy behaviors such as increasing physical activity, eating healthfully, practicing stress reduction techniques, having supportive relationships and focusing on one's own health and spiritual growth reported feeling more cheerful, calm, refreshed and energetic.

The burden and distress associated with cancer caregiving is well documented, and little can be done to change the actual circumstances of the caregiving experience such as the patient's acuity and illness trajectory, as well as the financial burden. Caregivers frequently report feeling as if their lives are completely out of their control [37]. Engaging in healthy behaviors may be one activity that caregivers can have a sense of control over and that will result in actual benefits. Furthermore, there appears to be an additive effect to health behaviors whereby engaging in one positive behavior may trigger secondary positive health behaviors [38, 39]. For example, by having individuals engage in stress reduction techniques, they may sleep better, which in turn may give them more energy to participate in

physical activity, which may then improve their energy and mood, thereby improving their interpersonal relationships.

A challenge faced by care providers who want to assist caregivers in adopting healthier behaviors will be that, in addition to feeling that they are unable to leave the side of their care recipient, they often don't want to. Caregivers report that they willingly put aside their own needs and neglect their own self-care in order to meet the needs of their loved one [40], and they may view taking time away from the patient as selfish and may feel guilty about it. For this reason, care providers not only need to be creative in coaching caregivers to find ways to incorporate healthy behaviors into their lives, they may need to give caregivers permission to do so. They can do this by pointing out the health risks associated with caregiving, and emphasizing the importance of caregivers prioritizing their own health, if for no other reason than that they will be better able to provide good care to their loved one if they maintain their own levels of energy and health.

While the findings of this study are important, they are not without limitations. The sample size was relatively small, and the sample included some caregivers of individuals receiving HSCT for non-cancerous conditions, making it difficult to generalize the findings specifically to cancer caregivers. These analyses were performed using data collected just prior to hospital discharge, a time when levels of stress, sleep disturbance and fatigue are likely to be high, but also a time when caregivers' health behavior practices might not be indicative of their norm. This was a secondary data analysis from baseline data from a convenience sample of individuals recruited for a cognitive-behavioral intervention study. Thus, selection bias might be present. The cross-sectional nature of this study does not allow one to draw definitive conclusions about causation, as we are only able to draw inferences about the relationship between health behaviors with sleep and fatigue in caregivers. All of the measures used in the study are self-report measures and are not without shortcomings. For example, the concept of health behaviors is very general, and it is unlikely that engaging in health promoting activities such as visiting one's health care provider actually have an impact on sleep and fatigue. While most of the measures performed reliably well in this study, however, Chronbach's alpha for the PSQI was slightly below the standard.

The findings of this study are important. Cancer caregivers experience burden and distress, and these things appear to contribute to problems with sleep and fatigue. However, in this population of caregivers, those individuals who engaged in healthy behaviors reported better sleep quality and less fatigue. While clinicians likely cannot change the patient's illness severity and trajectory, both of which will affect the caregiver's levels of burden and distress, we might be able to assist caregivers in improving their health behaviors, which in turn help them to sleep better and feel less fatigued.

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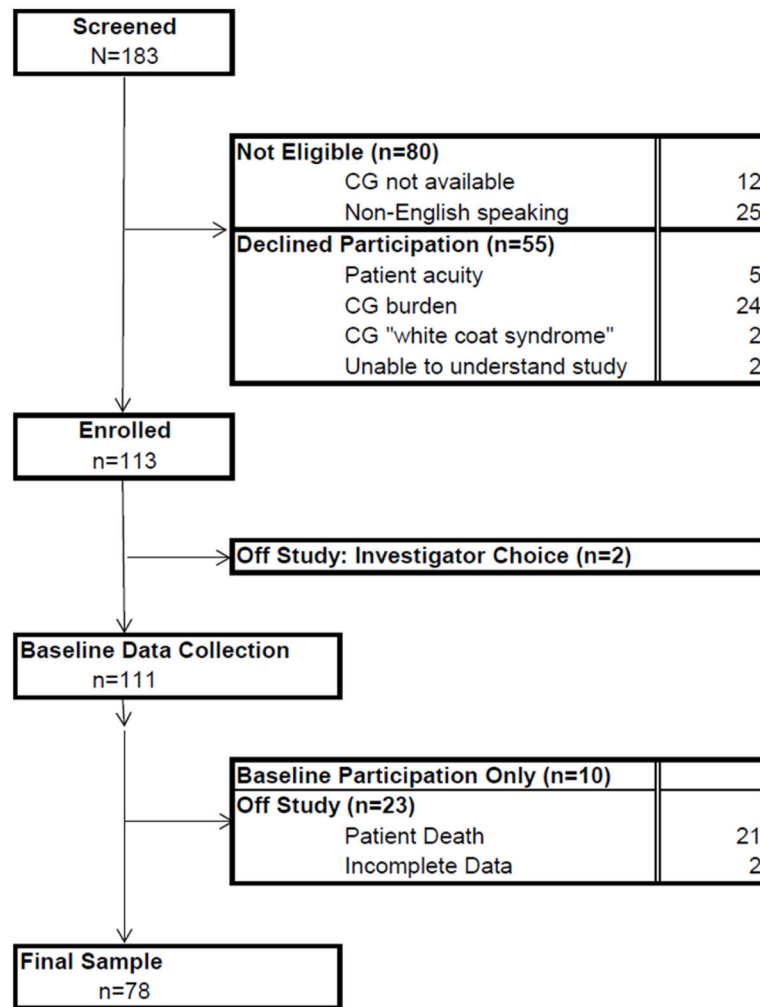
Figure 1.
Recruitment and enrollment algorithm

Table 1

Demographics and clinical characteristics of patients (n=58) and caregivers (n=78)

Characteristic	n (%) Total (n=78)
Caregiver	
Age, mean (SD) range	52.4 (12.8) 25–79
Gender	
Female	55 (70.5)
Race/Ethnicity	
White/Non-Hispanic	58 (74.4)
Hispanic	4 (5.1)
African American/Asian/American Indian/Other	16 (20.5)
Married, yes	68 (87.2)
Education	
High School	14 (17.9)
Some College	30 (38.5)
College Degree (Undergraduate or Graduate)	34 (43.6)
BMI*	
Normal (<25)	28 (36.4)
Overweight (25–29.9)	26 (33.8)
Obese (30)	23 (29.9)
Chronic Health Conditions, yes	47 (60.3)
Mean (SD) range	1.3 (1.4) 0–5
Sleep medications, yes	2 (2.6)
	Total (n=57)
Patients	
Primary Disease	
Lymphoma/Multiple Myeloma	29 (50.9)
Leukemia	13 (22.8)
Non-malignant disease	15 (26.3)
Transplant type	
Reduced Intensity Conditioning	50 (87.7)
Myeloablative	7 (12.3)
Graft type	
HLA- related donor	36 (63.2)
HLA- unrelated donor	21 (36.8)
Stem Cell Source	
Peripheral blood	56 (98.2)
Cord	1 (1.8)

SD, standard deviation; BMI, body mass index; HLA, human leukocyte antigen.

*
n=77

Table 2

Descriptive statistics of study variables (n=78)

	M (SD) Min–Max
CRA	
Total caregiver burden	51.2 (9.8) 28–75
BSI[a]*	
Global Severity Index (GSI)	48.3 (9.7) 35–71
Significant Distress, n (%)	*6 (7.8)*
HPLP-II	
Total score	2.6 (0.51) 1.6–3.8
Health responsibility	2.4 (0.6) 1–3.8
Nutrition	2.6 (0.7) 1.1–3.9
Physical activity	2.1 (0.7) 1–3.8
Interpersonal relations	3.0 (0.6) 1.7–4.0
Spiritual growth	3.0 (0.6) 1.8–4.0
Stress management	2.4 (0.6) 1.4–4.0
PSQI[b]**	
Total Score	6.4 (3.6) 0–17
Poor Sleep Quality, n (%)	*50 (65.8)*
MFSI	
Total score *	7.0 (17.4) −24–60
General *	6.4 (5.7) 0–23
Physical	2.4 (3.7) 0–20
Emotional	5.1 (4.1) 0–17
Mental	4.2 (4.0) 0–16
Vigor	11.3 (5.6) 0–24

CRA, Caregiver Reaction Assessment; BSI, Brief Symptom Inventory; HPLP-II, Health Promoting Lifestyle Profile-II; PSQI, Pittsburgh Sleep Quality Index; MFSI, Multidimensional Fatigue Symptom Inventory.

[a] Global Severity Index t-scores ≥ 63 or a t-score ≥ 63 on two or more Brief Symptom Inventory subscales are indicative of significant distress.

[b] PSQI score >5=poor sleep quality.

* n=77,

**n=74.

Table 3

Final regression models predicting total scores for sleep quality and fatigue

	PSQI[a]	MFSI[b]
	B (SE)	
	p	
Age	−.006 (.006)	−.032 (.009)
	.271	.000
Gender	.208 (.174)	−.077 (.260)
	.238	.768
BMI	.015 (.014)	.012 (.018)
	.268	.492
CRA	.023 (.008)	.019 (.013)
	.010	.131
BSI	.027 (.011)	.109 (.016)
	.014	.000
HPLP-II	−.408 (.172)	−.966 (.256)
	.021	.000

CRA, Caregiver Reaction Assessment; BSI, Brief Symptom Inventory; HPLP-II, Health Promoting Lifestyle Profile-II; PSQI, Pittsburgh Sleep Quality Index; MFSI, Multidimensional Fatigue Symptom Inventory; B, unstandardized coefficient; SE, standard error; *p*, significance. Both PSQI and MFSI scores were square root transformed. Gender coded: Males = 1, females = 2. Note: For the PSQI, increasing scores indicate worsening sleep quality.

[a]$F=8.928$, $df_1=6$, $df_2=65$, $p<.001$, Adjusted $R^2=.401$

[b]$F=27.252$, $df_1=6$, $df_2=68$, $p<.001$, Adjusted $R^2=.680$