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Sleep-Wake Circadian Activity Rhythms and Fatigue in Family Caregivers of Oncology Patients

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Abstract

Background—Little is known about the relationships between sleep/wake circadian activity rhythms and fatigue in family caregivers (FCs) of oncology patients.

Objectives—In a sample of FCs of oncology patients, to describe values for nocturnal sleep/rest, daytime wake/activity, and circadian activity rhythm parameters measured using actigraphy and to evaluate the relationships between these subjective and objective measures of sleep disturbance and self-reported fatigue severity.

Methods—FCs (n=103) completed self-report measures for sleep disturbance (i.e., Pittsburgh Sleep Quality Index, General Sleep Disturbance Scale) and fatigue (Lee Fatigue Scale) and wore wrist actigraphs for 48 hours prior to beginning radiation therapy. Spearman rank correlations were calculated between variables.

Results—Approximately 40% to 60% of FCs experienced sleep disturbance depending on whether clinically significant cutoffs for the subjective or objective measures were used to calculate occurrence rates. In addition, these FCs reported moderate levels of fatigue. Only a limited number of significant correlations were found between the subjective and objective measures of sleep disturbance. Significant positive correlations were found between fatigue and subjective, but not objective measures of sleep disturbance. The amplitude of circadian activity rhythm was not related to any objective sleep measure but was correlated with self-report of longer sleep onset latency.

Conclusions—A significant percentage of FCs experience clinically meaningful disturbances in sleep-wake circadian activity rhythms. These disturbances occur primarily in sleep maintenance.

Implications for Practice: FCs need to be assessed, along with patients, for sleep disturbance and appropriate interventions initiated for them and for the patient.

INTRODUCTION

As noted by Berger in her state of the science paper,¹ “patients with cancer and their caregivers often experience sleep-wake disturbances, particularly insomnia. However, this pervasive and distressing symptom is widely ignored” (p. E165). While the number of

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studies on sleep disturbance in oncology patients is increasing (for reviews see ¹⁻⁶), only a limited number of studies have evaluated for sleep disturbance in the family caregivers (FCs) of oncology patients. ⁷⁻¹⁷

Descriptive Studies of Sleep Disturbance in FCs of Oncology Patients

In the first descriptive study of sleep disturbance in FCs of oncology patients with advanced cancer (n=51),¹² 95% of the FCs reported severe sleep problems measured using the Pittsburgh Sleep Quality Index (PSQI). In a subsequent analysis of interviews from the same sample,⁷ FCs described severe fluctuations in sleep patterns over time. In a third paper from this sample,¹¹ less functional coping, less mastery, higher levels of neuroticism, and higher levels of depression explained 41% of the variance in sleep disturbance.

Four additional studies¹⁴⁻¹⁷ have provided information on sleep disturbance in FCs of oncology patients. In a study of primarily female (78%) FCs of gastric cancer patients who were receiving chemotherapy in Korea (n=103),¹⁴ 80% reported poor sleep quality using the PSQI. Poor sleep quality was moderately correlated with fatigue ($r=0.34$, $p<.01$). In another study of the quality of sleep in primarily female (53.3%) FCs of Turkish cancer patients (n=90),¹⁷ 72.2% reported poor sleep quality using the PSQI. The most commonly cited reasons for sleep disturbance were emotional distress, financial problems, and inadequate support systems.

In a third study of primarily male (82.0%) FCs of Taiwanese patients with breast cancer (n=61),¹⁵ 54% reported poor sleep quality using the PSQI. In this study, poor sleep quality was associated with decreases in quality of life (QOL). In the most recent study, that used both subjective and objective measures of sleep disturbance,¹⁶ 58 FCs of patients with advanced cancer were assessed to determine the prevalence of sleep-wake disturbances, to monitor the amount of daytime spent in activity and rest, and to examine the relationships between sleep and other symptoms. Based on their self-reports, 41% of the FCs reported poor sleep quality. Based on the objective measure, 46% had a sleep efficiency index below the cutoff for clinically significant sleep disturbance. Poor sleep quality was associated with higher levels of anxiety.

In the only longitudinal study of sleep disturbance in FCs of oncology patients,⁸ 10 FCs were evaluated on a weekly basis using subjective and objective measures of sleep disturbance. A large amount of inter-individual variability was found in FCs' levels of sleep disturbance over the 10 weeks of the study. Findings across these studies suggest that sleep disturbance is a common problem that affects between 40% and 90% of FCs of oncology patients. In addition, sleep disturbance is associated with increases in depressive symptoms, anxiety, and fatigue and has a negative impact on FCs' QOL.

Fatigue in FCs of Oncology Patients

Findings from a recent review of symptoms in FCs of oncology patients,¹⁸ suggest that fatigue is a common problem in FCs. While wide variability in fatigue severity was noted across studies, overall FCs reported moderate levels of fatigue. While several studies found that sleep disturbance was associated with higher levels of fatigue in patients who underwent radiation therapy (RT),¹⁹⁻²¹ only one study found a similar relationship in FCs of oncology patients.¹⁴

Given the growing number of FCs who provide care to oncology patients in the home^{22,23} and the paucity of published data, detailed information on sleep/wake and circadian activity rhythm parameters and their associations with fatigue in FCs is needed for comparative purposes in future studies. Therefore, the purposes of this study, in a sample of FCs of oncology patients who were about to start RT, were to describe values for nocturnal sleep/

rest, daytime wake/activity, and circadian activity rhythm parameters measured using actigraphy and to evaluate the relationships between these objective parameters and subjective ratings of sleep disturbance and fatigue severity. It was hypothesized that a high percentage of FCs would report clinically meaningful levels of sleep disturbance and that significant correlations would be found between objective sleep/wake circadian activity rhythm parameters and subjective ratings of sleep disturbance and fatigue severity.

METHODS

Participants and Settings

This descriptive, correlational study is part of a larger, longitudinal study that evaluated multiple symptoms in patients who underwent primary or adjuvant RT and their FCs.^{24,25} Although it is difficult to determine when a family member assumes the role of a caregiver, in most studies of symptoms in FCs,²⁶ the caregiver role is linked to the trajectory of the patient's treatment. Therefore, to obtain a "baseline" assessment of symptoms, FCs were recruited with the patients before the initiation of RT.

Patients and their FCs were recruited from RT departments in a Comprehensive Cancer Center and a community-based oncology program at the time of the patient's simulation visit. After recruitment of the patients, they were asked to identify the person most involved in their care (i.e., their FC). If the FC was with the patient, the research nurse explained the study and obtained written informed consent from the FC. FCs who were not with the patient were contacted by phone to determine their interest in study participation. The research nurse visited those FCs at home, obtained written informed consent, and had them complete the study questionnaires and begin wearing the wrist actigraph.

FCs were eligible to participate if they: were ≥ 18 years of age; were able to read, write, and understand English; gave written informed consent; had a Karnofsky Performance Status (KPS) score of ≥ 60 ; were living with the patient; and did not have a diagnosed sleep disorder (e.g., sleep disordered breathing, narcolepsy, restless leg syndrome).

Theoretical Framework

The theoretical framework for the study was the Theory of Symptom Management (TSM), which was developed by faculty members in the Center for Symptom Management at the University of California, San Francisco.²⁷⁻²⁹ As it relates to this analysis, the symptom experience dimension includes an individual's perceptions of sleep disturbance, physical fatigue and energy, and attentional fatigue, an evaluation of the meaning of the symptoms, and response to the symptoms. The symptom management strategies dimension includes both the self-care strategies that individuals use for themselves and the treatments that clinicians may prescribe. The outcomes dimension specifies that outcomes emerge from symptom management strategies as well as from the symptom experience. The TSM places the experience of symptom management within the context of the domains of nursing science — namely person, health and illness, and environment. The focus of this analysis is on the symptom experience dimension of the TSM, specifically how the experience of sleep disturbance, physical fatigue and energy, and attentional fatigue are related to each other in a sample of FCs of oncology patients at the initiation of RT.

Instruments

The study instruments included a demographic questionnaire, the KPS scale,³⁰ the PSQI,³¹ the General Sleep Disturbance Scale (GSDS),³² the Lee Fatigue Scale (LFS),³³ and the Attentional Function Index (AFI).³⁴ Objective data on sleep-wake circadian activity rhythms were obtained by continuous noninvasive monitoring of activity over 48 hours using a wrist

motion sensor (Mini Motionlogger Actigraph, Ambulatory Monitoring Inc., Ardsley, NY).^{35–37}

The demographic questionnaire obtained information on age, gender, marital status, education, ethnicity, employment status, living arrangements, the presence of a number of co-morbid conditions, and the FC's relationship with the patient.

Subjective ratings of sleep disturbance were evaluated using the PSQI and the GSDS. The PSQI consists of 19 items designed to assess the quality of sleep in the past month. The global PSQI score is the sum of the seven component scores (i.e., subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medication, daytime dysfunction). Each component score ranges from 0 to 3 and the global PSQI score ranges from 0 to 21. Higher global and component scores indicate more severe complaints and a higher level of sleep disturbance. A global PSQI score of >5 indicates a significant level of sleep disturbance.³¹ The PSQI has established internal consistency, test-retest reliability, and construct validity.^{31,38,39} In this study, the Cronbach's alpha for the global PSQI score was 0.68.

The GSDS consists of 21-items designed to assess the quality of sleep in the past week. Each item is rated on a 0 (*never*) to 7 (*everyday*) numeric rating scale (NRS). The GSDS total score is the sum of the seven subscale scores (i.e., quality of sleep, quantity of sleep, sleep onset latency, mid-sleep awakenings, early awakenings, medications for sleep, excessive daytime sleepiness) that can range from 0 (*no disturbance*) to 147 (*extreme sleep disturbance*). Each mean subscale score can range from 0 to 7. Because the GSDS items are rated on a scale of 0 (never) to 7 (every day), the subscale scores provide an estimation of the number of days per week that a patient experiences a particular problem. Higher total and subscale scores indicate higher levels of sleep disturbance. Mean subscale scores of ≥ 3 and a GSDS total score of ≥ 43 indicate a significant level of sleep disturbance.⁴⁰ The GSDS has well-established validity and reliability in shift workers, pregnant women, and patients with cancer and HIV.^{19,32,41} In the current study, the Cronbach's alpha for the GSDS total score was .79.

Subjective ratings of physical fatigue and energy were evaluated using the LFS.³³ The LFS consists of 18 items that are each rated on a 0 to 10 NRS. Total fatigue and energy scores were calculated as the mean of the 13 fatigue items and the 5 energy items, with higher scores indicating greater fatigue severity and higher levels of energy. Respondents were asked to rate each item based on how they felt "right now," within 30 minutes of awakening (i.e., morning fatigue, morning energy), and prior to going to bed (i.e., evening fatigue, evening energy). The LFS was used with healthy individuals^{33,42} and in patients with cancer and HIV.^{19,25,43,44} Cutoff scores of ≥ 3.2 and ≥ 5.6 indicate high levels of morning and evening fatigue, respectively.⁴⁰ Cutoff scores of ≤ 6.0 and ≤ 3.5 indicate low levels of morning and evening energy, respectively. The LFS was chosen for this study because it is relatively short, easy to administer, and has well established validity and reliability. In this study, Cronbach's alphas for evening and morning fatigue at baseline were .95 and .96, respectively. Cronbach's alphas for evening and morning energy were .95 and .96, respectively.

Subjective ratings of attentional fatigue were evaluated using the AFI. The AFI consists of 16 items that are each rated on a 0 to 10 NRS. A mean AFI score was calculated, with higher scores indicating greater capacity to direct attention and, therefore, lower levels of attentional fatigue.³⁴ Based on a previously conducted analysis of the frequency distributions of AFI scores, attentional fatigue can be grouped into categories of functional status (i.e., patients who score < 5.0 functioning poorly and experiencing high levels of

attentional fatigue, patients who score 5.0 to 7.5 functioning moderately well and experiencing moderate levels of attentional fatigue, patients who score > 7.5 functioning well and experiencing low levels of attentional fatigue.⁴⁵ The AFI has established reliability and validity.^{34,46} In the current study, Cronbach's alpha for the AFI was 0.95.

Objective data on sleep-wake circadian activity rhythm parameters were obtained by continuous noninvasive monitoring of activity over 48 hours using wrist actigraphy. Seven nocturnal sleep/rest, four daytime wake/activity, and six circadian activity rhythm parameters were selected from those identified by a National Cancer Institute sponsored conference,³ an expert panel that recommended a standard set of research assessments in insomnia,⁴⁷ and recently published studies.^{48,49}

Wrist actigraphy was validated with EEG measures of sleep and awakenings in men and women with both healthy and disturbed sleep patterns.^{36,37,47} It provides continuous motion data using a battery-operated wristwatch-size microprocessor that senses motion with a piezoelectric beam and detects movement in all three axes. The accompanying Action 4® software (Ambulatory Monitoring Inc., Ardsley, NY) allows analysis of activity and nonactivity as well as automatic scoring of sleep and wake episodes in minutes. Actigraphy scores, calculated using specific algorithms, correlate with polysomnography in adults at greater than 90%.³⁷

Study Procedures

After obtaining written informed consent, FCs completed the demographic questionnaire, KPS scale,³⁰ PSQI,³¹ GSDS,³² and AFI.³⁴ FCs were taught to complete the LFS³³ before going to bed each night (i.e., evening fatigue, evening energy) and upon arising each morning (i.e., morning fatigue, morning energy) for 2 consecutive days.

FCs wore the wrist actigraph to monitor nocturnal sleep/rest and daytime wake/activity continuously for two consecutive weekdays and completed the two day diary. FCs and patients wore the wrist actigraph on the same days prior to the initiation of RT. FCs were asked to use the event marker on the wrist actigraph to indicate "lights out" and "lights on" time. FCs reported no difficulties wearing the wrist actigraph. Since the actual time is important in the calculation of the amount of sleep obtained in the amount of time designated for sleep, having an additional source of information about nap times, bed times, and wake times is important. This information was recorded in a two day diary. Upon awakening, the FCs used the diary to indicate the number of awakenings during the night. FCs returned the questionnaires and actigraphs to the research nurse in the RT department.

Data Analysis

Data were analyzed using SPSS Version 18.⁵⁰ Descriptive statistics and frequency distributions were generated for the sample characteristics and symptom data. Spearman rank correlations were calculated between variables because of the ordinal nature of many of the variables.

Actigraphy files programmed in zero-crossing mode with 30 second intervals were analyzed using the Cole-Kripke algorithm in the Action 4® software (Ambulatory Monitoring Inc., Ardsley, NY) by two of the researchers (KL and CW). First, the file was scanned for missing data. Time limits were set for the 48-hour period. The file was reviewed and intervals were individually set for each day and night period using, in order of priority as decision guides: the event marker, diary data, channel data, and cascading movement data.

Because a minimum of 36 hours of continuous data are necessary to have sufficient data to calculate circadian rhythm parameters for a 24-hour period,⁵¹ if more than four hours of day

data or two hours of night data were missing, that day's or night's data were not used in the analyses. Cosinor analysis fit a cosine and sine wave to the wrist actigraphy data using a least-squares regression model. The mesor (24-hour adjusted mean value or y-intercept), amplitude, and acrophase (time of day for peak activity) were the circadian activity rhythm parameters obtained from the regression model.⁵² The autocorrelation coefficient for a 24-hour rhythm was obtained from the Action 4® software program.

All calculations used actual values. Adjustments were not made for missing data. Therefore, the cohort for each analysis was dependent on the largest set of available data across groups. A p-value of <0.05 was considered statistically significant.

RESULTS

Demographic and Clinical Characteristics

As summarized in Table 1, the majority of the FCs (n=103) were female (71.6%), White (78.4%), married/partnered (92.2%), and well educated, with a mean age of 61.7 ($\pm$ 10.4) years. FCs reported an average of 4.2 ($\pm$ 2.9) co-morbidities. The patients had prostate (59.2%), breast (26.2%), lung (7.8%) or brain (6.8%) cancer.

Subjective Ratings of Sleep Disturbance

Subjective ratings of sleep over the past month using the PSQI are listed in Table 2. The mean global PSQI score was 5.7 which is higher than the cutoff score of > 5. Fifty-nine percent of the FCs had a global PSQI score of > 5.

Subjective ratings of sleep over the past week using the GSDS are listed in Table 2. The mean total GSDS score was 39.1 which is slightly lower than the cutoff score of $\geq$ 43. However, 39% of the FCs had a total GSDS of $\geq$ 43. The GSDS subscale scores for quantity of sleep and mid-sleep awakenings had the highest scores, indicating that FCs perceived fewer hours of sleep than desired and a high number of mid-sleep awakenings on 4 out of 7 nights.

Nocturnal Sleep/Rest, Daytime Wake/Activity, and Circadian Activity Rhythm Parameters

Table 3 summarizes the data on sleep/rest, wake/activity, and circadian activity rhythm parameters obtained using actigraphy. Mean values for the sleep/rest parameters were within normal adult ranges³ for all of the variables except percentage of time awake at night, number of awakenings, total sleep time, and sleep efficiency. All of these values indicated that FCs experienced a significant amount of sleep disturbance. On average, FCs slept approximately 43 minutes during the day (range 0 to 399 minutes). In this sample, none of the mean values for the circadian rhythm parameters, except acrophase were within normal adult ranges.⁴⁹

Subjective Ratings of Fatigue and Energy

Table 2 summarizes the data on morning and evening fatigue and energy scores, as well as on attentional fatigue. While the mean morning and evening fatigue scores were below the cutoff values for clinically significant levels of fatigue, 29.7% and 31.7% of the FCs reported morning and evening fatigue scores above these cutoff values. In contrast, both morning and evening mean energy levels were below the cutoff scores which indicated low levels of energy in these FCs. The majority of FCs (53.0%) reported moderate to high levels of attentional fatigue.

Correlations Between Subjective Ratings of Sleep Disturbance and Nocturnal Sleep/Rest, Daytime Wake/Activity, and Circadian Activity Rhythm Parameters

Tables 4 and 5 summarize the significant correlations between PSQI and GSDS subscale and total scores and the various sleep/rest, wake/activity, and circadian activity rhythm parameters obtained with actigraphy. As shown in Table 4, a limited number of significant correlations were found between the PSQI subscale score of sleep duration and total sleep time and sleep period time. In addition, a significant negative correlation was found between the use of sleep medications and the wake/activity parameters obtained using actigraphy. As shown in Table 5, a significant correlation was found between the GSDS total score and sleep onset latency.

Correlations Between Fatigue and Energy Scores and Subjective Ratings of Sleep Disturbance and Nocturnal Sleep/Rest, Daytime Wake/Activity, and Circadian Activity Rhythm Parameters

As shown in Table 6, significant positive correlations were found between the majority of the subscale and total scores for both the PSQI and the GSDS and FCs' ratings of morning and evening fatigue. In addition, significant negative correlations were found between the majority of the subscale and total scores for both the PSQI and the GSDS and FCs' ratings of morning energy and attentional fatigue (i.e., indicating higher levels of attentional fatigue). Only two significant correlations were found between fatigue and energy scores and the objective sleep parameters.

DISCUSSION

This study is the first to provide detailed subjective and objective data on sleep-wake circadian activity rhythm parameters and fatigue in a sample of FCs of oncology patients prior to the initiation of the patient's RT. Based on these FCs' subjective responses to the PSQI and the GSDS, approximately 40% to 60% experienced clinically significant levels of sleep disturbance. This percentage is consistent with findings from two studies,^{15,16} but lower than findings from three studies of FCs of oncology patients.^{12,14,17} Using an actigraphy-sleep efficiency cutoff of < 80%,³ 29.5% of the FCs had a "bad night's sleep". Both the subjective and objective data suggest that a significant percentage of these FCs experience clinically meaningful levels of sleep disturbance. An evaluation of both the subjective and the objective data suggests that many of these FCs had difficulties with sleep maintenance.

Consistent with previous studies of oncology patients^{48,53,54} and elderly persons,⁵⁵ only a limited number of significant correlations were found between the nocturnal sleep/rest, daytime wake/activity, and circadian activity rhythm parameters obtained with actigraphy and the subjective ratings of various aspects of sleep disturbance using the PSQI and the GSDS. As shown in Tables 4 and 5, the strength of most of these correlations was small. As noted in a recent review,³⁵ numerous methodological challenges exist with actigraphy that may affect the strength of the correlations between objective and subjective measures of sleep disturbance. While the agreement between actigraphy and polysomnography is high in normal sleepers,^{37,56} it can be lower in persons with poor sleep quality⁵⁷ because these persons tend to lie in bed motionless but awake for long periods of time. In this situation, while actigraphy would overestimate sleep duration, FCs would report poor sleep quality and less sleep time. This disparity is confirmed in this study because using previously established cutoff scores for the subjective measures, approximately 40% to 60% of the FCs had significant sleep disturbance at the initiation of RT. However, using a sleep efficiency cutoff of < 80% for actigraphy, only 29.5% of the FCs were classified as having a significant level of sleep disturbance. In addition, in this study the FCs' sleep period time

ranged from 294 to 669 minutes (i.e., 5 hours to 11 hours) and based on the actigraphy data over 55% of FCs spent more than 8 hours in bed each night.

In several studies,^{35,48,54,55} recommendations were made to use both subjective and objective measures to evaluate sleep because these different approaches capture different aspects of disturbed sleep. For example, subjective measures capture the physical and mental aspects of sleep and the impact of sleep on an individual's ability to function. The use of multiple measures to evaluate sleep disturbance in FCs warrants investigation in future studies, particularly in terms of which measures are most sensitive to changes in various sleep parameters over time. This information is critical to the evaluation of the efficacy of pharmacologic and nonpharmacologic interventions to reduce sleep disturbance in FCs.

The PSQI was the most frequently used self-report measure to assess sleep quality in previous studies of FCs of oncology patients^{12,14,17} and in FCs of patients with Alzheimer's disease,⁵⁸ dementia,⁵⁹ and Parkinson's disease.⁶⁰ The PSQI global score for this sample (5.7 ± 3.2) was higher than values reported for healthy controls (range 1.9 to 3.1);^{31,61} comparable to some studies of FCs of patients with cancer¹⁴ and Parkinson's disease⁶⁰ (range 5.5 to 5.8), but lower than studies of FCs of patients with advanced cancer (11.3),¹² dementia,⁵⁹ or advanced Alzheimer's disease⁵⁸ (range 9.1 to 10.4). Differences among these studies, in the various PSQI subscale scores followed a similar pattern. Of note, based on the PSQI data, over 24% of the FCs in this study had problems with the initiation (sleep latency subscale) and 21% had problems with maintenance (sleep duration subscale) of sleep on two to three nights per week.

This study is the first to report data on subjective sleep disturbance using the GSDS in FCs of oncology patients. Using this scale, approximately 40% of the sample reported clinically significant levels of sleep disturbance. Similar to the PSQI, 19.8% of the FCs had a problem with the initiation of sleep (i.e., sleep onset latency). However, a higher percentage of FCs (i.e., 37.1% (early awakenings) to 67.7% (mid-sleep awakenings)) reported problems with sleep maintenance. To put the total GSDS score of the FCs in this study into context (i.e., 39.1 ± 16.0), these FCs had lower scores than patients with a variety of cancer diagnoses (i.e., 54.7 and 52.1).^{44,62} However, FCs in this study had GSDS total scores comparable to mothers in their third trimester of pregnancy (43.9)⁴² and women before and after hysterectomy (42.3 and 45.7),⁶³ but lower than nurses who worked nights (60.5) or rotated shifts (56.6).³²

Because the GSDS items are rated on a scale of 0 (never) to 7 (everyday), the subscale scores provide an estimation of the number of days per week that FCs experienced a particular problem. As shown in Table 2, 95% of the FCs in this study reported an insufficient amount of sleep on 4 or more days per week. In addition, almost 68% of the FCs experienced a clinically significant number of mid-sleep awakenings on almost 4 nights per week. Actigraphy data showed that FCs averaged 17.6 brief awakenings per night which is well above healthy adult values of 2 to 6 times per night.³ This high number of mid-sleep awakenings may be related to the fact that the majority of the FCs in this study was the spouses of patients with prostate cancer who awakened multiple times during the night to urinate. Taken together, data from the PSQI and the GSDS suggest that FCs in this study had problems with the maintenance of sleep.

Compared to healthy adult values,⁴⁹ all of the nocturnal sleep/rest actigraphy parameters, except sleep onset latency, were outside the normal ranges. When these FCs actigraphy data were compared to previous studies of FCs of patients with advanced cancer,^{8,16} sleep onset latency was shorter in this study (12.97 minutes) compared to Carter's study (40.0 to 45.0

minutes). In addition, total sleep time was longer in this study (406.5 minutes) compared to Carter's study (290 to 332 minutes). However, sleep efficiency (84%) was similar to Carter's study (73% to 80%), but worse than the study by Gibbin and colleagues (90% to 92%). The number of awakenings identified in this study using actigraphy (17.6) was significantly higher than that reported in studies of FCs of patients with Alzheimer's Disease (6.5)⁶⁴ or dementia (4.1).⁵⁹ Additional studies need to evaluate for differences in sleep-wake parameters in FCs of oncology patients at different points in the patient's disease and treatment trajectory.

Only two studies were found that reported on daytime wake/activity in FCs. In a study of FCs of patients with advanced cancer,¹⁶ based on actigraphy data, these FCs were inactive for 29% to 32% of the day and took 7 to 10 naps per day of approximately 8 to 10 minutes duration. In a study of FCs of patients with Alzheimer's Disease,⁶⁴ these FCs slept approximately 30 minutes per day which is slightly less than was found in the current study (43 minutes/day). The percent of time asleep per day in the current study (6%) was relatively low and is supported by the relatively small percentage of FCs who reported significant daytime dysfunction using both the PSQI (6.0%) and the GSDS (14.9%). This finding may be partially explained by the relatively high percentage of FCs (47.5%) who were employed. Additional research is warranted on when, how often, as well as the duration of naps in FCs of oncology patients because findings from several studies suggest that "power naps" (i.e., naps of less than 30 minutes duration that occur at around 3:00 PM) improve an individual's ability to function throughout the rest of the day.⁶⁵

While findings from several studies of primarily patients with breast cancer,^{48,49,66-70} suggest that circadian rhythm parameters are significantly disrupted in oncology patients, no studies were found that evaluated circadian activity rhythm parameters in FCs of oncology patients. In this study, acrophase values were similar to the general population. However, all of the other circadian rhythm parameters were below healthy adult values.⁴⁹ This finding suggests that these FCs had dampened circadian rhythms with low daytime activity and higher nighttime activity. However, because circadian rhythm data were collected for only 36 hours, additional research is warranted to confirm the findings from this study.

FCs in this study reported moderate levels of morning and evening fatigue. In addition, approximately 50% reported moderate levels of attentional fatigue. An important finding is that over 35% of the FCs in this study reported low levels of morning and evening energy. As expected, increased levels of morning fatigue, as well as attentional fatigue, and decreased levels of morning energy were associated with the majority of the subscale and total scores on the PSQI and the GSDS. However, fatigue and energy scores were not correlated with the majority of the actigraphy measures.

A number of study limitations need to be acknowledged. The sample was primarily female, White, and well educated with a mean age of 62 years. Therefore, these findings may not generalize to all FCs of patients with cancer. While the sample size was relatively small, this study provides important information on sleep-wake circadian activity rhythm parameters that can be used for comparative purposes. Ideally, actigraphy data should be collected for longer periods of time to study circadian rhythms. However, data were collected only on weekdays which eliminated changes in the various objective parameters that might occur on weekends. Therefore, these results should be interpreted with caution and not generalized to both weekdays and weekends. Finally, data were not available on the specific sleep medications that these FCs used or on other medications that could contribute to sleep disturbance.

Despite these limitations, findings from this study suggest that a significant percentage of FCs of oncology patients experience clinically meaningful disturbances in sleep-wake circadian activity rhythms. Additional research is warranted on how both subjective and objective parameters change over time; on which FCs are at greatest risk for these disturbances; on what factors contribute to sleep disturbance in these FCs; and on the efficacy of various pharmacologic and nonpharmacologic interventions to decrease the levels of disturbance in these FCs. In addition, the relationships between changes in patients' and FCs' subjective and objective sleep disturbance parameters need to be evaluated during and following the patients' cancer treatment.

As noted in a number of reviews,^{1,4,5} clinicians need to perform systematic assessments of FCs' sleep quality. These sleep assessments should focus on difficulty falling asleep and staying asleep and excessive daytime sleepiness. In addition, the impact of sleep disturbance on FCs' ability to function needs to be assessed. Oncology clinicians need to assist FCs and patients to follow basic sleep hygiene principles. For example, FCs and patients should be encouraged to establish regular sleep and wake times and to engage in regular exercise. FCs and patients need to be reminded to avoid excessive fluid intake and restrict the consumption of caffeinated beverages in the evening.¹ Implementation of these simple measures may improve FCs' and patients' sleep quality during and following cancer treatment.

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References

- Berger AM. Update on the state of the science: sleep-wake disturbances in adult patients with cancer. *Oncol Nurs Forum*. 2009; 36(4):E165–177. [PubMed: 19581220]
- Savard J, Morin CM. Insomnia in the context of cancer: a review of a neglected problem. *J Clin Oncol*. 2001; 19(3):895–908. [PubMed: 11157043]
- Berger AM, Parker KP, Young-McCaughan S, et al. Sleep wake disturbances in people with cancer and their caregivers: State of the science. *Oncol Nurs Forum*. 2005; 32(6):E98–126. [PubMed: 16270104]
- Clark J, Cunningham M, McMillan S, Vena C, Parker K. Sleep-wake disturbances in people with cancer Part II: Evaluating the evidence for clinical decision making. *Oncol Nurs Forum*. 2004; 31(4):747–771. [PubMed: 15252430]
- Vena C, Parker K, Cunningham M, Clark J, McMillan S. Sleep-wake disturbances in people with cancer Part I: An overview of sleep, sleep regulation, and effects of disease and treatment. *Oncol Nurs Forum*. 2004; 31(4):735–746. [PubMed: 15252429]
- Lee K, Cho M, Miaskowski C, Dodd M. Impaired sleep and rhythms in persons with cancer. *Sleep Med Rev*. 2004; 8(3):199–212. [PubMed: 15144962]
- Carter PA. Caregivers' descriptions of sleep changes and depressive symptoms. *Oncol Nurs Forum*. 2002; 29(9):1277–1283. [PubMed: 12370697]
- Carter PA. Family caregivers' sleep loss and depression over time. *Cancer Nurs*. 2003; 26(4):253–259. [PubMed: 12886115]
- Carter PA. Bereaved caregivers' descriptions of sleep: impact on daily life and the bereavement process. *Oncol Nurs Forum*. 2005; 32(4):741. [PubMed: 15990901]
- Carter PA. A brief behavioral sleep intervention for family caregivers of persons with cancer. *Cancer Nurs*. 2006; 29(2):95–103. [PubMed: 16565618]

11. Carter PA, Acton GJ. Personality and coping: predictors of depression and sleep problems among caregivers of individuals who have cancer. *J Gerontol Nurs.* 2006; 32(2):45–53. [PubMed: 16502761]
12. Carter PA, Chang BL. Sleep and depression in cancer caregivers. *Cancer Nurs.* 2000; 23(6):410–415. [PubMed: 11128119]
13. Carter PA, Mikan SQ, Simpson C. A feasibility study of a two-session home-based cognitive behavioral therapy-insomnia intervention for bereaved family caregivers. *Palliat Support Care.* 2009; 7(2):197–206. [PubMed: 19538802]
14. Cho MH, Dodd MJ, Lee KA, Padilla G, Slaughter R. Self-reported sleep quality in family caregivers of gastric cancer patients who are receiving chemotherapy in Korea. *J Cancer Educ.* 2006; 21(1 Suppl):S37–41. [PubMed: 17020500]
15. Chang EW, Tsai YY, Chang TW, Tsao CJ. Quality of sleep and quality of life in caregivers of breast cancer patient. *Psychooncology.* 2007; 16(10):950–955. [PubMed: 17315285]
16. Gibbins J, McCoubrie R, Kendrick AH, Senior-Smith G, Davies AN, Hanks GW. Sleep-wake disturbances in patients with advanced cancer and their family carers. *J Pain Symptom Manage.* 2009; 38(6):860–870. [PubMed: 19800196]
17. Aslan O, Sanisoglu Y, Akyol M, Yetkin S. Quality of Sleep in Turkish Family Caregivers of Cancer Patients. *Cancer Nurs.* 2009; 32(5):370–377. [PubMed: 19661798]
18. Swore Fletcher BA, Dodd MJ, Schumacher KL, Miaskowski C. Symptom experience of family caregivers of patients with cancer. *Oncol Nurs Forum.* 2008; 35(2):E23–44. [PubMed: 19405245]
19. Miaskowski C, Lee KA. Pain, fatigue, and sleep disturbances in oncology outpatients receiving radiation therapy for bone metastasis: A pilot study. *J Pain Symptom Manage.* 1999; 17(5):320–332. [PubMed: 10355211]
20. Stone P, Richards M, A'Hern R, Hardy J. Fatigue in patients with cancers of the breast or prostate undergoing radical radiotherapy. *J Pain Symptom Manage.* 2001; 22(6):1007–1015. [PubMed: 11738163]
21. Kiebert GM, Curran D, Aaronson NK, et al. Quality of life after radiation therapy of cerebral low-grade gliomas of the adult: results of a randomised phase III trial on dose response (EORTC trial 22844). EORTC Radiotherapy Co-operative Group. *Eur J Cancer.* 1998; 34(12):1902–1909. [PubMed: 10023313]
22. Yabroff KR, Kim Y. Time costs associated with informal caregiving for cancer survivors. *Cancer.* 2009; 115(18 Suppl):4362–4373. [PubMed: 19731345]
23. Tamayo GJ, Broxson A, Munsell M, Cohen MZ. Caring for the caregiver. *Oncol Nurs Forum.* 2010; 37(1):E50–57. [PubMed: 20044332]
24. Aouizerat BE, Dodd M, Lee K, et al. Preliminary evidence of a genetic association between tumor necrosis factor alpha and the severity of sleep disturbance and morning fatigue. *Biol Res Nurs.* 2009; 11(1):27–41. [PubMed: 19419979]
25. Miaskowski C, Paul SM, Cooper BA, et al. Trajectories of fatigue in men with prostate cancer before, during, and after radiation therapy. *J Pain Symptom Manage.* 2008; 35(6):632–643. [PubMed: 18358683]
26. Fletcher BA, Miaskowski C, Dodd MJ, Schumacher KL. A review of the literature on the symptom experience of family caregivers of patients with cancer. *Oncol Nurs Forum.* 2008; 35(2):E23–E44. [PubMed: 19405245]
27. Larson P, Carrieri-Kohlman V, Dodd MJ, et al. A model for symptom management. *Image.* 1994; 26(4):272–276.
28. Dodd M, Janson S, Facione N, et al. Advancing the science of symptom management. *J Adv Nurs.* 2001; 33(5):668–676. [PubMed: 11298204]
29. Humphreys, J.; Lee, KA.; Carrieri-Kohlman, V., et al. Theory of Symptom Management. In: Smith, MJ.; Liehr, PR., editors. *Middle Range Theory for Nursing.* 2. New York: Springer Publishing Company; 2008. p. 145-158.
30. Karnofsky D, Abelmann WH, Craver LV, Burchenal JH. The use of nitrogen mustards in the palliative treatment of carcinoma. *Cancer.* 1948; 1:634–656.

31. Buysse DJ, Reynolds CF 3rd, Monk TH, Berman SR, Kupfer DJ. The Pittsburgh Sleep Quality Index: a new instrument for psychiatric practice and research. *Psychiatry Res.* 1989; 28(2):193–213. [PubMed: 2748771]
32. Lee KA. Self-reported sleep disturbances in employed women. *Sleep.* 1992; 15(6):493–498. [PubMed: 1475563]
33. Lee KA, Hicks G, Nino-Murcia G. Validity and reliability of a scale to assess fatigue. *Psychiatry Res.* 1991; 36(3):291–298. [PubMed: 2062970]
34. Cimprich B. Attentional fatigue following breast cancer surgery. *Res Nurs Health.* 1992; 15(3):199–207. [PubMed: 1354883]
35. Berger AM, Wielgus KK, Young-McCaughan S, Fischer P, Farr L, Lee KA. Methodological challenges when using actigraphy in research. *J Pain Symptom Manage.* 2008; 36(2):191–199. [PubMed: 18400460]
36. Morgenthaler T, Alessi C, Friedman L, et al. Practice parameters for the use of actigraphy in the assessment of sleep and sleep disorders: an update for 2007. *Sleep.* 2007; 30(4):519–529. [PubMed: 17520797]
37. Ancoli-Israel S, Cole R, Alessi C, Chambers M, Moorcroft W, Pollak CP. The role of actigraphy in the study of sleep and circadian rhythms. *Sleep.* 2003; 26(3):342–392. [PubMed: 12749557]
38. Beck SL, Schwartz AL, Towsley G, Dudley W, Barsevick A. Psychometric evaluation of the Pittsburgh Sleep Quality Index in cancer patients. *J Pain Symptom Manage.* 2004; 27(2):140–148. [PubMed: 15157038]
39. Carpenter JS, Andrykowski MA. Psychometric evaluation of the Pittsburgh Sleep Quality Index. *J Psychosom Res.* 1998; 45(1 Spec No):5–13. [PubMed: 9720850]
40. Fletcher BS, Paul SM, Dodd MJ, et al. Prevalence, severity, and impact of symptoms on female family caregivers of patients at the initiation of radiation therapy for prostate cancer. *J Clin Oncol.* 2008; 26(4):599–605. [PubMed: 18235118]
41. Lee KA, DeJoseph JF. Sleep disturbances, vitality, and fatigue among a select group of employed childbearing women. *Birth.* 1992; 19(4):208–213. [PubMed: 1472269]
42. Gay CL, Lee KA, Lee SY. Sleep patterns and fatigue in new mothers and fathers. *Biol Res Nurs.* 2004; 5(4):311–318. [PubMed: 15068660]
43. Lee KA, Portillo CJ, Miramontes H. The fatigue experience for women with human immunodeficiency virus. *J Obstet Gynecol Neonatal Nurs.* 1999; 28(2):193–200.
44. Miaskowski C, Cooper BA, Paul SM, et al. Subgroups of patients with cancer with different symptom experiences and quality-of-life outcomes: a cluster analysis. *Oncol Nurs Forum.* 2006; 33(5):E79–89. [PubMed: 16955115]
45. Cimprich B, So H, Ronis DL, Trask C. Pre-treatment factors related to cognitive functioning in women newly diagnosed with breast cancer. *Psychooncology.* 2005; 14(1):70–78. [PubMed: 15386786]
46. Jansen CE, Dodd MJ, Miaskowski CA, Dowling GA, Kramer J. Preliminary results of a longitudinal study of changes in cognitive function in breast cancer patients undergoing chemotherapy with doxorubicin and cyclophosphamide. *Psychooncology.* 2008; 17(12):1189–1195. [PubMed: 18506671]
47. Buysse DJ, Ancoli-Israel S, Edinger JD, Lichstein KL, Morin CM. Recommendations for a standard research assessment of insomnia. *Sleep.* 2006; 29(9):1155–1173. [PubMed: 17040003]
48. Berger AM, Farr LA, Kuhn BR, Fischer P, Agrawal S. Values of sleep/wake, activity/rest, circadian rhythms, and fatigue prior to adjuvant breast cancer chemotherapy. *J Pain Symptom Manage.* 2007; 33(4):398–409. [PubMed: 17397701]
49. Berger AM, Wielgus K, Hertzog M, Fischer P, Farr L. Patterns of circadian activity rhythms and their relationships with fatigue and anxiety/depression in women treated with breast cancer adjuvant chemotherapy. *Support Care Cancer.* Apr 19.2009
50. SPSS. SPSS for Windows (Version 18). Chicago, Illinois: SPSS, Inc; 2010.
51. Berger AM, Sankaranarayanan J, Watanabe-Galloway S. Current methodological approaches to the study of sleep disturbances and quality of life in adults with cancer: A systematic review. *Psychooncology.* 2007; 16(5):401–420. [PubMed: 16929462]

52. Lentz MJ. Time-series analysis--cosinor analysis: a special case. *West J Nurs Res.* 1990; 12(3): 408–412. [PubMed: 2363294]
53. Ancoli-Israel S, Liu L, Marler MR, et al. Fatigue, sleep, and circadian rhythms prior to chemotherapy for breast cancer. *Support Care Cancer.* 2006; 14(3):201–209. [PubMed: 16010529]
54. Wang SY, Chang HJ, Lin CC. Sleep Disturbances Among Patients With Non-Small Cell Lung Cancer in Taiwan: Congruence Between Sleep Log and Actigraphy. *Cancer Nurs.* 2010; 33(1):E11–17. [PubMed: 19926974]
55. Van Den Berg JF, Van Rooij FJ, Vos H, et al. Disagreement between subjective and actigraphic measures of sleep duration in a population-based study of elderly persons. *J Sleep Res.* 2008; 17(3):295–302. [PubMed: 18321246]
56. Sadeh A, Hauri PJ, Kripke DF, Lavie P. The role of actigraphy in the evaluation of sleep disorders. *Sleep.* 1995; 18(4):288–302. [PubMed: 7618029]
57. Sivertsen B, Omvik S, Havik OE, et al. A comparison of actigraphy and polysomnography in older adults treated for chronic primary insomnia. *Sleep.* 2006; 29(10):1353–1358. [PubMed: 17068990]
58. McKibbin CL, Ancoli-Israel S, Dimsdale J, et al. Sleep in spousal caregivers of people with Alzheimer's disease. *Sleep.* 2005; 28(10):1245–1250. [PubMed: 16295209]
59. Castro CM, Lee KA, Bliwise DL, Urizar GG, Woodward SH, King AC. Sleep patterns and sleep-related factors between caregiving and non-caregiving women. *Behav Sleep Med.* 2009; 7(3):164–179. [PubMed: 19568966]
60. Pal PK, Thennarasu K, Fleming J, Schulzer M, Brown T, Calne SM. Nocturnal sleep disturbances and daytime dysfunction in patients with Parkinson's disease and in their caregivers. *Parkinsonism Relat Disord.* 2004; 10(3):157–168. [PubMed: 15036171]
61. Buysse DJ, Reynolds CF 3rd, Monk TH, Hoch CC, Yeager AL, Kupfer DJ. Quantification of subjective sleep quality in healthy elderly men and women using the Pittsburgh Sleep Quality Index (PSQI). *Sleep.* 1991; 14(4):331–338. [PubMed: 1947597]
62. Pud D, Ben Ami S, Cooper BA, et al. The symptom experience of oncology outpatients has a different impact on quality-of-life outcomes. *J Pain Symptom Manage.* 2008; 35(2):162–170. [PubMed: 18082357]
63. Kim KH, Lee KA. Sleep and fatigue symptoms in women before and 6 weeks after hysterectomy. *J Obstet Gynecol Neonatal Nurs.* 2009; 38(3):344–352.
64. McCurry SM, Vitiello MV, Gibbons LE, Logsdon RG, Teri L. Factors associated with caregiver reports of sleep disturbances in persons with dementia. *Am J Geriatr Psychiatry.* 2006; 14(2):112–120. [PubMed: 16473975]
65. Dhand R, Sohal H. Good sleep, bad sleep! The role of daytime naps in healthy adults. *Curr Opin Pulm Med.* 2006; 12(6):379–382. [PubMed: 17053484]
66. Levin RD, Daehler MA, Grutsch JF, et al. Circadian function in patients with advanced non-small-cell lung cancer. *Br J Cancer.* 2005; 93(11):1202–1208. [PubMed: 16265345]
67. Mormont MC, Langouet AM, Claustrat B, et al. Marker rhythms of circadian system function: a study of patients with metastatic colorectal cancer and good performance status. *Chronobiol Int.* 2002; 19(1):141–155. [PubMed: 11962672]
68. Fernandes R, Stone P, Andrews P, Morgan R, Sharma S. Comparison between fatigue, sleep disturbance, and circadian rhythm in cancer inpatients and healthy volunteers: evaluation of diagnostic criteria for cancer-related fatigue. *J Pain Symptom Manage.* 2006; 32(3):245–254. [PubMed: 16939849]
69. Roscoe JA, Morrow GR, Hickok JT, et al. Temporal interrelationships among fatigue, circadian rhythm and depression in breast cancer patients undergoing chemotherapy treatment. *Support Care Cancer.* 2002; 10(4):329–336. [PubMed: 12029433]
70. Pati AK, Parganiha A, Kar A, Soni R, Roy S, Choudhary V. Alterations of the characteristics of the circadian rest-activity rhythm of cancer in-patients. *Chronobiol Int.* 2007; 24(6):1179–1197. [PubMed: 18075806]

Table 1

Demographic Characteristics of the Family Caregivers (n= 103)

Characteristic	Mean (Standard Deviation) and Range
Age (years)	61.69 (10.37) – 34 to 86
Education (years)	15.76 (3.00) – 9 to 22
Karnofsky Performance Status score	93.79 (10.64) – 50 to 100
Number of comorbidities	4.18 (2.92) – 0 to 12
	%
Gender	
Male	28.4
Female	71.6
Ethnicity	
White	78.4
Nonwhite	21.6
Married/partnered	92.2
Relationship to the patient	
Spouse/partner	91.2
Significant other	4.9
Child	2.0
Friend	2.0
Lives with patient	99.0
Employed	47.5
Children at home	19.5
Parent living at home	2.4
Patient's cancer diagnosis	
Prostate cancer	59.2
Breast cancer	26.2
Lung cancer	7.8
Brain tumor	6.8

Table 2
Pittsburgh Sleep Quality Index (PSQI), General Sleep Disturbance (GSDS), Fatigue, and Energy Scores in Family Caregivers (n=103)

Pittsburgh Sleep Quality Index					
Subscale and Global PSQI scores (range of possible scores)	Mean	Standard deviation	Mean score range 0 to 0.9 n (%)	Mean score range 1.0 to 1.9 n (%)	Mean score range 2.0 to 3.0 n (%)
Sleep quality (0 to 3)	0.89	0.67	27 (27.0)	58 (58.0)	15 (15.0)
Sleep latency (0 to 3)	0.92	0.92	39 (39.0)	37 (37.0)	24 (24.0)
Sleep duration (0 to 3)	0.87	0.82	35 (36.8)	40 (42.1)	20 (21.1)
Habitual sleep efficiency (0 to 3)	0.60	0.93	60 (63.2)	20 (21.0)	15 (15.8)
Sleep disturbances (0 to 3)	1.29	0.50	2 (2.0)	67 (67.0)	31 (31.0)
Use of sleep medications (0 to 3)	0.47	0.94	75 (75.8)	9 (9.0)	15 (15.2)
Daytime dysfunction (0 to 3)	0.69	0.58	37 (37.0)	57 (57.0)	6 (6.0)
			Mean score < 5	Mean score between 5 and 8	Mean score > 8
Global PSQI Score (0 to 21)	5.66	3.16	41 (41.0)	42 (42.0)	17 (17.0)
General Sleep Disturbance Score					
Subscale and Total GSDS scores (range of possible scores)	Mean	Standard deviation	Range	<3 n (%)	≥ 3 n (%)
Quality of sleep (0 to 7)	2.64	1.65	0.00 – 7.00	51 (51.0)	49 (49.0)
Quantity of sleep (0 to 7)	4.58	1.32	0.50 – 7.00	5 (5.0)	95 (95.0)
Sleep onset latency (0 to 7)	1.50	1.85	0.00 – 7.00	81 (80.2)	20 (19.8)
Mid-sleep awakenings (0 to 7)	4.06	2.40	0.00 – 7.00	32 (32.3)	67 (67.7)
Early awakenings (0 to 7)	2.30	2.15	0.00 – 7.00	61 (62.9)	36 (37.1)
Medications for sleep (0 to 7)	0.24	0.49	0.00 – 2.67	101 (100.0)	0 (0.0)
Excessive daytime sleepiness (0 to 7)	1.83	1.15	0.00 – 6.43	86 (85.1)	15 (14.9)
				Mean score < 43	Mean score ≥ 43
Total score (0 to 147)	39.07	16.02	12.00 – 84.00	62 (61.4)	39 (38.6)
Physical Fatigue and Energy and Attentional Fatigue					
Variable	Mean	Standard Deviation	Range	n (%) below the cutoff score	n (%) above the cutoff score
Morning fatigue ^a	2.27	1.87	0.00 – 7.77	73 (70.3)	30 (29.7)
Evening fatigue ^b	4.50	1.96	0.23 – 8.69	71 (68.3)	32 (31.7)
Morning energy ^c	5.79	2.06	0.00 – 10.00	45 (42.6)	58 (57.4)

Pittsburgh Sleep Quality Index					
Subscale and Global PSQI scores (range of possible scores)	Mean	Standard deviation	Mean score range 0 to 0.9 n (%)	Mean score range 1.0 to 1.9 n (%)	Mean score range 2.0 to 3.0 n (%)
Evening energy ^d	4.31	1.81	0.00 – 8.40	68 (65.3)	35 (34.7)
Attentional fatigue ^e	7.19	1.76	1.06 – 9.88	50 (47.0)	53 (53.0)

^a Cutoff for high level of morning fatigue = ≥ 3.2;

^b Cutoff for high level of evening fatigue = ≥ 5.6,

^c Cutoff for low level of morning energy = ≤ 6.0,

^d Cutoff for low level of evening energy = ≤ 3.5;

^e Cutoff for moderate to severe attentional fatigue - ≤ 7.5

Table 3

Nocturnal Sleep/Rest, Daytime Wake/Activity, and Circadian Activity Rhythm Parameters Obtained with Wrist Actigraphy in Family Caregivers (n = 103)

Variable	Healthy Adult Values(see reference 3)	Mean	Standard deviation	Range
Nocturnal Sleep/Rest				
Sleep onset latency (minutes)	< 20 minutes	12.97	10.49	1.00 – 66.00
Percent wake at night (% TST)	< 10% of TST	12.72	10.12	1.51 – 49.90
Number of awakenings	2 to 6 times per night	17.59	9.43	3.00 – 44.50
Wake duration (minutes)	Unknown	3.40	2.13	0.50 – 10.93
Total sleep time (minutes)	420–540 minutes	406.49	78.78	157.00 – 564.00
Sleep period time (minutes)	Unknown	484.62	78.13	293.50 – 668.50
Sleep efficiency (%)	<80% indicates a bad night's sleep	83.98	10.93	44.58 – 96.97
Daytime Wake/Activity				
Total sleep time (TST - minutes)	Unknown	42.98	67.52	0.00 – 399.02
Total wake time (minutes)	Unknown	677.02	67.52	320.98 – 720.00
Sleep percent day(% 720 minutes 9:00 – 20:59)	Unknown	5.97	9.38	0.00 – 55.42
Wake percent day	Unknown	94.03	9.38	44.58 – 100.00
Circadian Activity Rhythm				
Mesor (24 hour rhythm adjusted mean of activity counts; higher values represent more robust activity)	138.2 (8.4) to 150.3 (17.7)	67.70	8.74	49.75 – 87.42
Amplitude (Peak or trough value of the cosine curve minus the mesor; represents the rhythmic change of an individual's activity during the 24 hour period)	109 (23.4) to 112.4 (4.9)	53.20	9.40	30.20 – 70.59
Peak activity (Sum of the mesor and the amplitude values; it represents more robust circadian activity rhythms)	Approximately 250–260	120.90	13.75	89.14 – 148.25
Acrophase (Actual clock time of the peak amplitude)	Early afternoon between 2:00 and 3:00 PM	14:31	1:10	12:18–18:41
Circadian quotient (Strength of the circadian rhythm calculated by dividing the amplitude by the mesor)	Closer to 1.00	0.80	0.15	0.41 – 1.11
Autocorrelation (Comparison of the regularity and consistency of the rhythm from one day to the next day)	Range –1 to +1; optimal = 1	0.45	0.14	0.09 – 0.81

Table 4

Significant Correlations Between Pittsburgh Sleep Quality Index (PSQI) Scores and Nocturnal Sleep/Rest, Daytime Wake/Activity, and Circadian Activity Rhythm Parameters Obtained with Wrist Actigraphy in Family Caregivers (n=103)

Variable	PSQI total score	Sleep quality	Sleep latency	Sleep duration	Habitual sleep efficiency	Sleep disturbances	Use of sleep medications	Daytime dysfunction
Nocturnal Sleep/Rest								
Sleep onset latency								
Percent wake at night								
Number of awakenings							-.29 ^b	
Wake duration								
Total sleep time				-.33 ^b				
Sleep period time				-.28 ^b	.27 ^b			
Sleep efficiency (%)								
Daytime Wake/Activity								
Total sleep time							-.30 ^b	
Total wake time							-.30 ^b	
Sleep percent day							-.30 ^b	
Wake percent day							-.30 ^b	
Circadian Activity Rhythm								
Mesor								
Amplitude			.35 ^a					
Peak activity								
Acrophase								
Circadian quotient			.37 ^a					
Autocorrelation								

^a p<.05,

^b p<.01

Table 5
Significant Correlations Between General Sleep Disturbance (GSDS) Scores and Nocturnal Sleep/Rest, Daytime Wake/Activity, and Circadian Activity Rhythm Parameters Obtained with Wrist Actigraphy in Family Caregivers (n=103)

Variable	GSDS total score	Quality of Sleep	Quantity of sleep	Sleep onset latency	Mid-sleep awakenings	Early awakenings	Medications for sleep	Excessive daytime sleepiness
Nocturnal Sleep/Rest								
Sleep onset latency	.21 ^a			.25 ^a				
Percent wake at night								
Number of awakenings								
Wake duration								
Total sleep time								
Sleep in period time					.22 ^a			
Sleep efficiency								
Daytime Wake/Activity								
Total sleep time								
Total wake time								
Sleep percent day								
Wake percent day								
Circadian Activity Rhythm								
Mesor						-.30 ^a		
Amplitude								
Peak activity								
Acrophase								
Circadian quotient								
Autocorrelation								

^a p<.05

Table 6

Significant Correlations Between Morning and Evening Fatigue and Energy Scores and Attentional Fatigue and Nocturnal Sleep/Rest, Daytime Wake/Activity, and Circadian Activity Rhythm Parameters Obtained with Wrist Actigraphy in Family Caregivers (n=103)

Variable	Morning Fatigue	Evening Fatigue	Morning Energy	Evening Energy	Attentional Fatigue
Pittsburgh Sleep Quality Index					
Total score	.40 ^c		-.29 ^b		-.33 ^b
Sleep quality	.33 ^b		-.27 ^b		
Sleep latency					-.28 ^b
Sleep duration					-.23 ^a
Habitual sleep efficiency	.24 ^a				
Sleep disturbances	.25 ^a		-.20 ^d		-.26 ^b
Use of sleep medications					.20 ^a
Daytime dysfunction	.37 ^c	.31 ^b	-.38 ^c		-.52 ^c
General Sleep Disturbance Scale					
Total score	.37 ^c	.31 ^b	-.38 ^c		-.32 ^b
Quality of sleep	.31 ^b		-.33 ^b		
Quantity of sleep	.34 ^b	.20 ^d			
Sleep onset latency	.25 ^a	.29 ^b	-.24 ^a		-.21 ^a
Mid-sleep awakenings					
Early awakenings					-.30 ^b
Medications for sleep					
Excessive daytime sleepiness	.29 ^b	.34 ^b	-.32 ^b		-.43 ^c
Nocturnal Sleep/Rest					
Sleep onset latency			-.25 ^a		
Percent wake at night					
Number of awakenings					-.21 ^a
Wake duration					

Variable	Morning Fatigue	Evening Fatigue	Morning Energy	Evening Energy	Attentional Fatigue
Total sleep time					
Sleep period time					
Sleep efficiency					
Daytime Wake/Activity					
Total sleep time					
Total wake time					
Sleep percent day					
Wake percent day					
Circadian Activity Rhythm					
Mesor					
Amplitude					
Peak activity					
Acrophase					
Circadian quotient					
Autocorrelation					

^a p<.05,
^b p<.01,
^c p<0.0001