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Sleep Loss and its Health Impact Among Family Caregivers of Persons with a Primary Malignant Brain Tumor

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This dissertation, SLEEP LOSS AND ITS HEALTH IMPACT AMONG FAMILY CAREGIVERS OF PERSONS WITH A PRIMARY MALIGNANT BRAIN TUMOR by Jean D. Pawl was prepared under the direction of the candidate's dissertation committee. It is accepted by the committee members in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Nursing by the Byrdine F. Lewis School of Nursing and Health Professions, Georgia State University.

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ABSTRACT

SLEEP LOSS AND ITS HEALTH IMPACT AMONG FAMILY CAREGIVERS OF PERSONS WITH A PRIMARY MALIGNANT BRAIN TUMOR

by

JEAN D. PAWL

Sleep impairments for caregivers are multifactorial. Assumptions are that caregivers of those with primary malignant brain tumors (PMBT) are similar to caregivers of persons with dementia as cognitive impairments are present at diagnosis. The shorter trajectory of PMBTs and rapid deterioration of recipients' health may influence sleep in caregivers of persons with a PMBT. The purposes of this study were to use a sleep impairment model to characterize caregiver sleep using objective and subjective measures, and to examine sleep loss effects on psychosocial and physiologic health outcomes.

A secondary data analysis using baseline data from a larger study of mind-body interactions in caregivers of family members with PMBTs was used. Caregiver data included standardized questionnaires, serum blood draw, and three-day sleep-wake activity data from an accelerometer. Analyses included descriptive statistics, correlations, t-tests, and hierarchical regression models.

Caregivers (*N* = 133) were White (94%), female (69.2%) spouses (75.2) and on average 52 years old (*SD* = 11.8). Care recipients were mainly White males of similar age with a highly malignant glioma (57.4%). Sleep latency was longer (35 min, $SD = 34.5$), with shorter total sleep time (TST) (357 min, $SD = 84.6$) and more frequent wake after sleep onset (WASO; 15.1%, $SD = 9.2$) than in the general population. Caregivers reported high anxiety (59.4%). Caregiver comorbidities and care recipient functioning explained higher perceptions of health ($R^2 = 26$, $F(2, 84) = 14.94$, $p < .001$). Whereas, longer TST, more WASO and poorer sleep quality explained poorer quality of life ($R^2 = .27$, $F(4, 66) = 6.19$, $p < .001$). Sleep loss variables explained little variance in physical health status, interleukin-1ra and interleukin-6 levels, fatigue, depressive symptoms, spiritual health, social support, and work limitations.

Nurses need to assist caregivers with anxiety management and ways to improve sleep at time of PMBT diagnosis. Sleep impairments place these caregivers at risk for physical and mental health problems, and compromise their ability to continue in the role.

SLEEP LOSS AND ITS HEALTH IMPACT AMONG FAMILY CAREGIVERS OF PERSONS WITH A PRIMARY MALIGNANT BRAIN TUMOR

by

JEAN D. PAWL

A DISSERTATION

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This dissertation is dedicated in loving memory of my father, Norman Runge, diagnosed with a glioblastoma multiforme March 21, 2006, died June 20, 2006, and his caregiver, my mother, Jean Runge, and to all the other caregivers and care recipients who must walk this journey.

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LIST OF ABBREVIATIONS

AASM	American Academy of Sleep Medicine
ACS	American Cancer Society
ADL	Activity of Daily Living
BMI	Body Mass Index
CBTRUS	Central Brain Tumor Registry of the United States
CES-D	Center for Epidemiologic Studies – Depression Scale
CRA	Caregiver Reaction Assessment
EEG	Electroencephalogram
ESS	Epworth Sleepiness Scale
FACIT-Sp	Functional Assessment of Chronic Illness Therapy- Spiritual
FSQOL	Fox Simple Quality of Life
GBM	Glioblastoma Multiforme
GH	Growth Hormone
HPA	Hypothalamic-Pituitary-Adrenocortical
IADL	Instrumental Activity of Daily Living
IL	Interleukin
ISEL	Interpersonal Support Evaluation List
KPS	Karnofsky Performance Scale
MDASI-BT	M.D. Anderson Symptom Inventory - Brain Tumor

MOS SF-36	Medical Outcomes Study - Short Form 36
NREM	Nonrapid Eye Movement
PMBT	Primary Malignant Brain Tumor
POMS	Profile of Mood States
PSG	Polysomnography
PSQI	Pittsburgh Sleep Quality Index
QOL	Quality of Life
REM	Rapid Eye Movement
SE	Sleep Efficiency
SWS	Slow Wave Sleep
TIB	Time in Bed
TNFα	Tumor Necrosis Factor Alpha
TST	Total Sleep Time
WASO	Wake After Sleep Onset
WLQ	Work Limitations Questionnaire

CHAPTER I

INTRODUCTION

This chapter provides an overview of the significance of providing care to a family member with a primary malignant brain tumor (PMBT) and its impact on sleep. In theory, sleep loss in these caregivers has a deleterious effect on health. In this study, a sleep impairment model as applied to caregivers of those with a PMBT is proposed.

Overview of PMBTs and Caregiving

PMBTs account for 2% of all cancers yet are associated with disproportionate morbidity and mortality (Omay & Vogelbaum, 2009; Schnell & Tonn, 2009). Persons, typically males in their mid-60s or older, diagnosed with the most common PMBT, malignant gliomas, have an average life expectancy of 14 months after diagnosis (Omay & Vogelbaum, 2009). At the time of diagnosis, those with PMBTs often present with focal deficits, which can include headache (56%); memory loss (35%); cognitive changes (34%); motor deficits (33%); language deficits (32%); seizures (32%); personality changes (23%), visual disturbances (22%), and/or other symptoms such as nausea and vomiting, changes in level of consciousness, and sensory deficits (Chandana, Movva, Arora, & Singh, 2008). During the course of the treatment trajectory, which may include a craniotomy for tumor debulking, radiation therapy for 6 weeks, and chemotherapy (Armstrong, 2009; Schnell & Tonn, 2009), the person with a PMBT experiences the inability to perform activities of daily living (ADLs), cognitive impairments, and neuropsychiatric symptoms related to the disease as well as the treatments. The care for the person with PMBT falls upon members of the family, as the physical and cognitive manifestations of tumor invasion and treatment do not warrant hospitalization (Sherwood et al., 2006).

There has been extensive research on the effects of providing care on the caregiver's emotional and physical health, defined in the literature as caregiver burden (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007; Kim & Schulz, 2008; Pinquart & Sorensen, 2003a, 2003b; Van Den Wijngaart, Vernooij-Dassen, & Felling, 2007; Vitaliano, Zhang, & Scanlan, 2003). Intertwined in caregiver burden are sleep disturbances, which have been shown to worsen physical and psychological health (Perrin, Heesacker, Stidham, Rittman, & Gonzalez-Rothi, 2008; Wilcox & King, 1999). Caregivers of those with PMBTs report sleep disturbances as well (Muñoz et al., 2008; Sherwood et al., 2006; Wideheim, Edvardsson, Pahlson, & Ahlstrom, 2002). However, the effects of sleep disruptions and their impact on health outcomes have not been the focus of any study in the scant literature on caregivers of persons with PMBTs. It is unknown (a) what types of sleep disturbances are reported; (b) the antecedents to the sleep disturbances; and (c) if these sleep disturbances impact family caregivers' daily functioning and quality of life (QOL).

Sleep disturbances affect the complex interaction between (a) the circadian pacemaker rhythms (such as sleep/wake, thermal [body temperature], neuroendocrine [heart rate, hormones such as melatonin and cortisol], and immune [cytokines]), (b) the sleep homeostat (the pressure to sleep, i.e., sleepiness or the lack of pressure to sleep, alertness), and (c) the architecture of the sleep cycles (Birchler-Pedross et al., 2009; Moldofsky, 1995; Walker, 2009). Increased sleepiness due to sleep losses is associated with negative mood (McCurry, Logsdon, Teri, & Vitiello, 2007) and impaired cognitive and motor functioning (Banks & Dinges, 2011; Curcio, Casagrande, & Bertini, 2001). For caregivers who must provide care and support to care recipients with PMBTs, sleep disruptions may adversely impact their ability to meet the challenges of caring for a loved one with cognitive, physical, and neuropsychiatric impairments and whose disease may change rapidly.

The research in caregivers of adults with PMBTs is limited: most studies are qualitative or descriptive in nature and limited to Caucasian female spousal caregivers who provided care for less than 3 years—most for 6 months or less (Cashman et al., 2007; Keir, 2007; Keir et al., 2006; Muñoz et al., 2008; Salander & Spetz, 2002; Schmer, Ward-Smith, Latham, & Salacz, 2008; Sherwood, Given, Doorenbos, & Given, 2004; Sherwood et al., 2006; Sherwood et al., 2007; Wideheim et al., 2002). Rapid changes in care recipient functioning from PMBTs has been associated with increased levels of depressive symptoms (Bradley et al., 2009; Schubart, Kinzie & Farace, 2008; Sherwood et al., 2006; Sherwood et al., 2007; Strang & Strang, 2001; Strang, Strang, & Ternestedt, 2001), anxiety (Cashman et al., 2007; Keir et al., 2006; Schubart et al., 2008) and fatigue (Cashman et al., 2007; Schubart et al., 2008; Sherwood et al., 2004) in these caregivers. Furthermore, greater dependence of the care recipient has been associated with an increase in caregiver distress and feelings of burden (Sherwood et al., 2006). Whether sleep disturbances create or add to caregiver depressive symptoms, anxiety, or fatigue is unknown in this caregiving population. Brooks, Girgenti, and Mills (2009) found that sleep complaints put an individual at risk for development of depression, particularly in women, yet the directionality of the impairment has not been clarified, as depressed persons typically experience sleep complaints such as prolonged sleep latency, increased wakefulness in the night, and decreased sleep efficiency (Swanson, Hoffmann, & Armitage, 2010).

In other cancer caregiving populations, sleep impairments in the form of insomnia, other nocturnal sleep disturbances (such as arousals by the care recipient), and daytime fatigue are common complaints (Berger et al., 2005). Poor sleep has been associated with reactive depression that interferes with daily functioning, QOL, and ability to provide care (Berger et al., 2005). Chronic sleep loss has only recently been associated with increased stress in caregivers of persons with cancer (Berger et al., 2005). These sleep impairments also are noted in other caregiving populations, such as dementia care and the frail elderly (Iecovich, 2008; McCurry et al., 2007) and may lead to institutionalization of the care recipient (Chenier, 1997; Pollack & Perlick, 1991; Stewart, 1995). Furthermore, sleep impairments can continue to be present long after the caregiving situation has terminated either through the death or institutionalization of the care recipient (Carlsson & Nilsson, 2007; Carter, 2005; Carter, Mikan, & Simpson, 2009; Waldrop, 2007). The continued sleep impairments may be a result of habituation to the sleep conditions imposed by caregiving and effects on the circadian system (Rogers & Dinges, 2008). Carter et al. (2009) reported that sleep pattern disturbances may continue for years after the care recipient’s death and that these prolonged disturbances are associated with increased incidence of depression and prolonged grief trajectory, which may be related to the effects of sleep deprivation on the neurochemistry of the sleep cycles (see discussion in Chapter II; Sculthorpe & Douglass, 2010).

Overview of Normal Sleep

Sleep is an interweaving of complex physiologic and behavioral processes that result in a reversible behavioral state of perceptual disengagement from and unresponsiveness to the environment (Carskadon & Dement, 2011). Sleep is divided into two stages: nonrapid eye movement sleep (NREM) and REM. Non-REM sleep consists of four stages that represent a continuum of sleep depth as seen on the electroencephalogram (EEG): Stage 1 is the lightest sleep stage in which a person is easily aroused, and Stage 4 is the deepest. Stages 3 and 4 are typically categorized together and called deep, delta, or slow wave sleep (SWS). During SWS, voluntary muscle control and tone remains intact while mental activity becomes slower. In contrast, REM sleep is characterized by (a) a high level of brain activity, resembling waking activity on the EEG, and (b) paralysis of the voluntary muscles, which is believed to keep people from acting out their dreams (Carskadon & Dement, 2011). Non-REM sleep accounts for about 75% to 80% of total sleep—REM sleep for 20% to 25%. A typical night’s sleep includes four to six sleep cycles lasting approximately 90 to 110 minutes with NREM and REM alternating during each cycle (Carskadon & Dement, 2011; Carter, 2005; Vena, Parker, Cunningham, Clark, & McMillan, 2004). Early in the night, the stages of SWS dominate the sleep cycle, whereas in the latter half of the night, REM sleep prevails (Walker, 2009).

Sleep/wake is regulated through three distinct processes. The homeostatic process mediates the increase in sleep pressure while awake and the dissolution of sleep pressure during sleep. The circadian process is composed of alternating periods of high and low sleep propensities, which are independent of prior sleep and waking. The ultradian process occurs during sleep and is composed of the alteration between the NREM and REM sleep states (Kunz & Herrmann, 2000). These processes interact to determine the timing, duration, and architecture of sleep. Sleep propensity in the circadian process is almost opposite in phase to the homeostatic process. Circadian sleep propensity is low in the evening time when the homeostatic sleep pressure is high, which allows an individual to stay awake with appropriate daytime brain functioning. In contrast, circadian sleep propensity is high in the early morning when the homeostatic sleep pressure is low, facilitating consolidated sleep during the night. REM sleep in the ultradian process is heavily influenced by the circadian process, which results in more REM sleep during the early morning hours of sleep (Beersma, 1998; Kunz & Herrmann, 2000).

Researchers have hypothesized that two major functions of sleep are restoration of the brain and the creation of memory through encoding and consolidation. The restoration of the brain hypothesis is supported through research findings that (a) sleep deprivation affects cognitive functioning more than physical functioning, (b) quiet waking rests the body but does not satisfy the need to sleep, and (c) there are predictable EEG pattern changes after sleep deprivation in SWS (Kunz & Herrmann, 2000). Furthermore, in rat studies, neuronal degeneration occurs in the supraoptic nucleus of the hypothalamus after sleep deprivation, leading to a predictable syndrome of temperature dysregulation, weight loss, skin lesions, and eventual death if sleep deprivation continues for 2 to 3 weeks (Eiland et al., 2002). Sleep deprivation has a profound effect on the encoding of emotional stimuli, particularly positive and neutral stimuli, whereas negative emotional stimuli are more resistant to the effects of sleep loss (Walker, 2009). The hypothesis of memory consolidation is supported by an increase in REM sleep after learning of formal tasks and exposure to high stimulation environments (Kunz & Herrmann, 2000). Furthermore, people tested after a night of sleep have been found to have memories more resistant to interference with other information across the day than those who experienced disrupted sleep (Walker, 2009).

Use of a Sleep Impairment Model for Caregivers of Those with PMBTs

Optimal sleep, defined by Hamilton, Nelson, Stevens, and Kitzman (2007) as between 6 and 8 1/2 hours of sleep, was associated with better psychological health, greater environmental mastery, positive relations with others, and fewer symptoms of anxiety and depression (*N* = 502). Sleep must occur in a regular pattern with only minimal disruptions to serve as a restorative function for the mind and body (Carter, 2005). During sleep, hormones are released, and neuronal restoration occurs to support memory and learning. Sleep mediates stress, anxiety, and tension and provides individuals with emotional, mental, and physical energy to accomplish the tasks of daily living and cope with stressful life events (Carter, 2005).

A sleep impairment model by Lee (2003) illustrates how impaired sleep quantity/quality can negatively influence daily functioning, QOL, and health of the individual. Sleep impairments may be in the form of sleep deprivation, sleep disruptions, or both, with all resulting in sleep loss (see Figure 1). This loss of sleep may impact health adversely through its effects on physical, cognitive/behavioral, emotional, and social components of the person experiencing the sleep impairment.

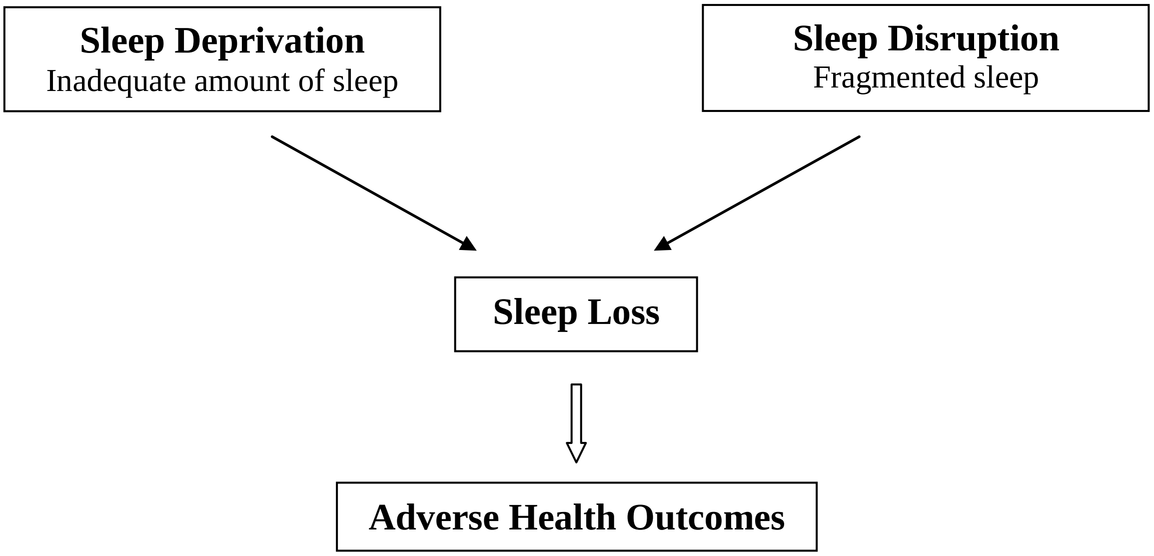

Figure 1. Conceptual model of impaired sleep. From “Impaired Sleep“ by K. A. Lee, 2003, In V. Carrieri-Kohlman, A. M. Lindsey, & C. M. West (Eds.), Pathophysiological phenomena in nursing: Human responses to illness (p. 364). St. Louis, MO: Saunders. Copyright 2003 by Elsevier. Reprinted with permission.

Risk Factors for Sleep Deprivation and Sleep Disruption

There are three primary categories of risk factors for sleep deprivation and sleep disruption: environmental, personal, and developmental (Lee, 2003). Unexpected environmental noise or light during sleep results in arousals from sleep and subsequent maintenance insomnia. For older adults who experience less-deep sleep than younger adults, there is less capacity to sleep through loud noises and bright daylight (Lee, 2003). The personal or the internal environment is influenced by physiological and psychological stressors. Stressors can include poor nutrition, situational crises, inadequate or overly strenuous physical activity, disease processes, or medical treatments. Chronic stress also is known to inhibit the immune response and the cytokines involved in sleep regulation (Lee, 2003) whereas acute stress releases catecholamines and other stimulants, making sleep difficult. Other personal stressors may include work schedules or travels across time zones. In caregiving, the stress may be the additional responsibilities caregivers assume when a family member is ill. Developmental risk factors are formed from chronic unhealthy lifestyle behaviors that develop in young adulthood as a result of stressful life situations or undiagnosed sleep disorders. Behaviors can include drinking caffeinated beverages in the evening, poor diet, lack of exercise, and/or watching late night television while in bed. These behaviors perpetuate poor sleep and the continuation of the behaviors in a futile effort to obtain sleep whereas in reality, the behaviors exacerbate the poor sleep (Lee, 2003).

Sleep Deprivation

Lee et al. (2004) defined sleep deprivation as an inadequate amount of sleep. Inadequate amounts of sleep may be related to delayed bedtime, early wake time, poor sleep hygiene, or performing multiple roles or having multiple responsibilities such as when being a caregiver. Other factors impacting sleep quantity include environmental noxious stimuli and circadian phase desynchronosis through jet lag, shiftwork, or seasonal light/dark exposure. Further factors can occur because of developmental adaptations during infancy/childhood, adolescence/puberty, pregnancy/postpartum, and aging/retirement. Lastly, total sleep time (TST) may be impacted by grief and bereavement. For caregivers who may assume multiple roles and tasks, sleep restrictions may occur in the context of performing these duties and result in being awake during the night. In persons with PMBTs, the tumor and its treatment may lead to insomnia, excessive daytime sleepiness, and increased nighttime arousals (Gapstur, Gross, & Ness, 2009). These sleep disruptions in the care recipient may (a) awaken caregivers in the night, (b) cause delay in going to bed, or (c) cause early morning arousals in response to the care recipient’s needs. Sleep obtained in the day or at irregular times that may be a result of providing care is of poorer quality than sleep obtained during usual nighttime sleep (Achermann & Borbely, 2011; Lee et al., 2004).

Sleep Disruption

Sleep disruption in the impaired sleep model is defined as fragmented sleep (Lee et al., 2004). Fragmentation can be a result of sleep disorders such as sleep apnea, restless leg syndrome, or parasomnias. Other disruptions can be related to hyperarousal from stress and anxiety, violence, or post-traumatic events. Drugs such as caffeine, nicotine, or other stimulants or those with the opposite effect such as alcohol and other central nervous system depressants also can cause fragmented sleep by affecting sleep rhythm. Health conditions and/or the treatments of these conditions may fragment sleep; for example, the nocturia of cardiac and renal dysfunction can cause arousal from sleep. Other health conditions implicated in sleep fragmentation include esophageal reflux; obesity; immobility; pain; pulmonary disorders such as asthma or chronic obstructive pulmonary disease; gastro-intestinal disorders such as irritable bowel syndrome or hiatal hernia; and neuroendocrine disorders such as diabetes, Alzheimer’s disease, Parkinson’s disease, pregnancy, and menopause. Traumatic experiences, relationships, situations at home or at work, or noisy or restless bed partners can be an environmental stressor and source of sleep loss (Lee et al., 2004). In the context of caregiving for persons with PMBTs, above and beyond caregiver sleep disorders or comorbidities, caregivers may experience increased stress and anxiety related to the gravity of the diagnosis and the rapidness in which the functioning of the person with a PMBT can decline. Persons suffering sleep fragmentation may or may not be aware of the disruptions in the night, much less the impact of sleep losses on personal health.

Adverse Health Outcomes Related to Sleep Loss

Sleep loss, particularly chronic losses (Banks & Dinges, 2011), puts a person at risk for adverse health outcomes. It matters not whether the sleep loss is a result of deprivation or disruption, or both. Health outcomes from sleep loss are categorized by Lee et al. (2004) as physiological, cognitive/behavioral, emotional, or social responses. Current literature shows that physiological responses to sleep loss include altered immune function (Benca & Quintans, 1997; Moldofsky, 1995; Von Kanel et al., 2006), altered metabolic/endocrine function (Moldofsky, 1995), and increased incidences of comorbidities such as hypertension (Von Kanel et al., 2006) and depression (Hamilton et al., 2007). Cognitive/behavioral responses include impaired daytime functioning, fatigue, increased risk for accidents and/or errors, impaired short-term memory loss, and impaired problem solving and coping (Banks & Dinges, 2011; Bonnet, 2011). Sleep loss effects on the emotional domain include altered mood and low motivation (Hamilton et al., 2007). Social responses to sleep loss include impaired social interactions, impaired family interactions, impaired work performance and productivity, and the increased use of health care services (Lee, 2003). Collectively, the adverse health outcomes resulting from sleep loss may affect one's overall QOL.

Caregiving for a Person with a PMBT and Sleep Loss

The nature of PMBTs, especially those that are highly malignant, and their associated shortened trajectory imposes great stress and strain on a caregiver. Families acknowledge that grieving the loss of their loved one starts before the actual death as they confront the loss of personhood and rapidly changing cognitive, physical, and neuropsychiatric impairments (Sherwood et al., 2004). The literature for this population describes and quantifies the depression and fatigue felt by these caregivers; however, no studies have examined sleep disturbances as a part of this depression and fatigue even though the sleep literature for other caregivers demonstrates a greater number of caregivers with sleep disturbances reporting depressive symptoms (Brummett et al., 2006; Carter & Chang, 2000; Castro et al., 2009; Kochar, Fredman, Stone, & Cauley, 2007; McCurry et al., 2007). In a study by Sherwood et al. (2006), the researchers briefly reported that awakening in the night by the care recipient caused disruptions, but how this interplays with the depressive symptoms and fatigue reported by these caregivers has not been studied. Families of those with brain tumors report that they live in constant anxiety and fear of losing their loved one (Wideheim et al., 2002), but how this anxiety associated with the uncertainty of the situation impacts sleep is not known. Furthermore, sleep loss may affect the caregiver's ability to respond to the care recipient, both physically and emotionally. By examining sleep loss characteristics of deprivation and disruption, caregiver characteristics, care recipient characteristics, and adverse health outcomes (see Figure 2), insights for future interventional studies that may assist caregivers during a time of great tension and turmoil may be developed.

Research Question and Hypotheses

Based on the theoretical model of impaired sleep and the context of providing care for the unforeseen and relatively rare diagnosis of PMBTs, the purposes of this study were to explore the influence of sleep disruptions and deprivations and resultant sleep loss on the health outcomes of caregivers of those with PMBTs. This study used a

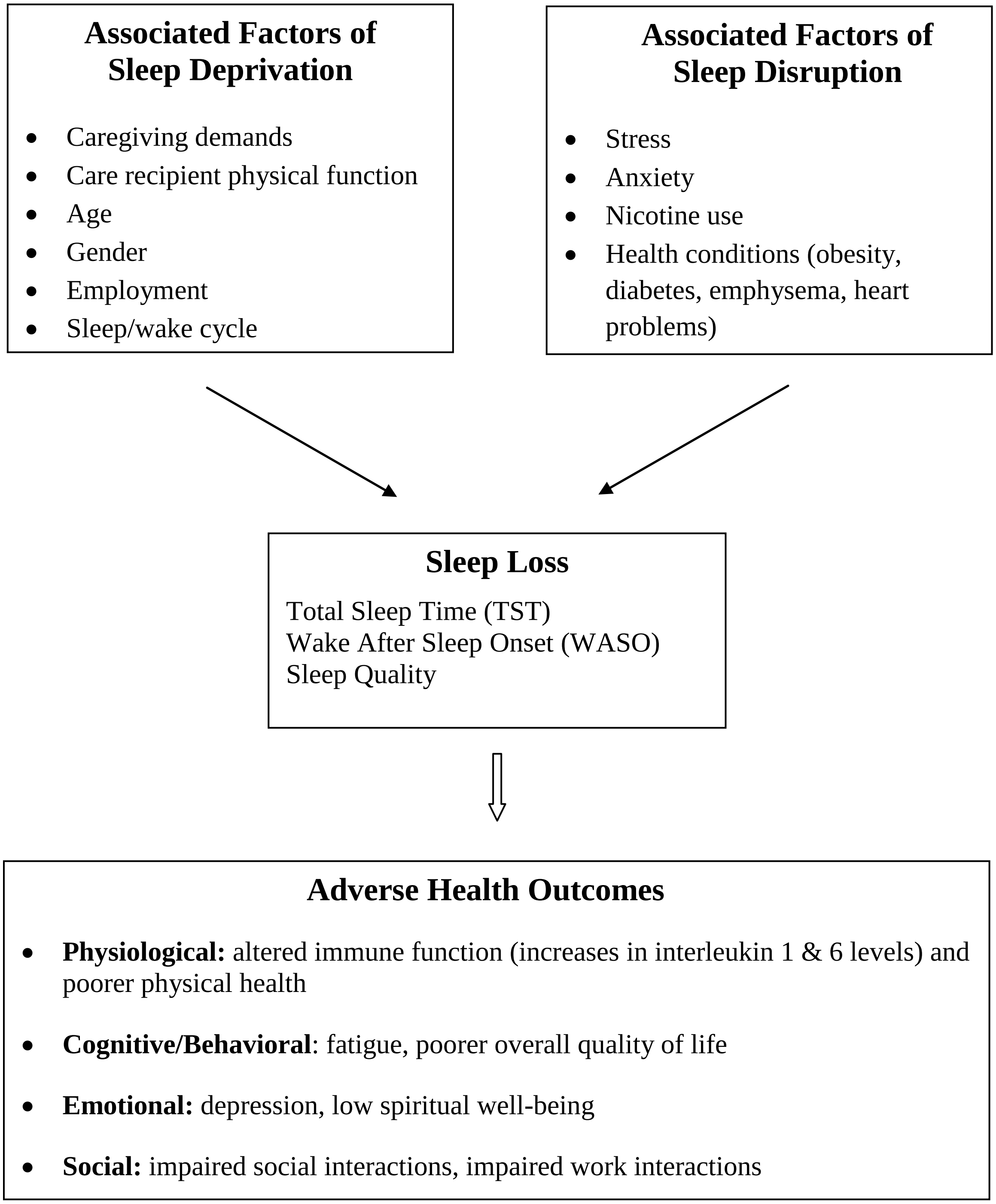

Figure 2. Conceptual model for sleep impairment for a caregiver of a person with a PMBT. Adapted from "Impaired Sleep" by K. A. Lee, 2003, In V. Carrieri-Kohlman, A. M. Lindsey, & C. M. West (Eds.), Pathophysiological phenomena in nursing: Human responses to illness (pp. 364). St. Louis, MO: Saunders. Copyright 2003 by Elsevier. Reprinted with permission.

secondary data analysis of baseline data of informal caregivers of those with PMBTs enrolled in the nonexperimental, longitudinal study, *Mind-Body Interactions in Neuro-Oncology Caregivers* (National Cancer Institute R01 [CA118711-02], Sherwood, PI, 2007), referred to in this study as the parent study. The specific aims of the proposed secondary analysis were (a) to examine the relationships among sleep disruption and sleep deprivation on perceived sleep quality and quantified sleep loss, (b) to examine the relationships among sleep quality and sleep loss on the health outcomes of the caregiver, and (c) to determine the contribution of the sleep disruptions and sleep deprivation to caregiver health outcomes.

Research Question

1. What are the sleep characteristics (sleep onset times, sleep awake time, TST, wake after sleep onset [WASO], naps, sleep efficiency, sleep/wake cycle) of family caregivers of those with PMBTs?

Hypotheses

In a sample of family caregivers providing care for persons with PMBTs:

1. Sleep deprivation (caregiving demands, a reflection of care recipient function; care recipient physical function; and employment) and sleep disruption (stress, anxiety, nicotine use, and health conditions) will contribute significant variance ($p < .05$) to sleep loss (TST, WASO, and sleep quality) while controlling for caregiver age and gender.

2. Sleep deprivation (caregiving demands, a reflection of care recipient function; care recipient physical function; and employment), sleep disruption (stress, anxiety, nicotine use, and health conditions), and sleep loss (TST, WASO, and sleep quality) will contribute significant variance ($p < .05$) to adverse physiological health outcomes (altered

immune function [increased serum levels of Interleukin 1 and Interleukin 6] and poorer physical health) while controlling for caregiver age and gender.

3. Sleep deprivation (caregiving demands, a reflection of care recipient function; care recipient physical function; and employment), sleep disruption (stress, anxiety, nicotine use, and health conditions), and sleep loss (TST, WASO, and sleep quality) will contribute significant variance (*p* < .05) to adverse cognitive/behavioral outcomes (higher fatigue and poorer overall QOL) while controlling for caregiver age and gender.

4. Sleep deprivation (caregiving demands, a reflection of care recipient function; care recipient physical function; and employment), sleep disruption (stress, anxiety, nicotine use, and health conditions), and sleep loss (TST, WASO, and sleep quality) will contribute significant variance (*p* < .05) to adverse emotional outcomes (higher depression and lower spiritual well-being) while controlling for caregiver age and gender.

5. Sleep deprivation (caregiving demands, a reflection of care recipient function; care recipient physical function; and employment), sleep disruption (stress, anxiety, nicotine use, and health conditions), and sleep loss (TST, WASO, and sleep quality) will contribute significant variance (*p* < .05) to adverse social outcomes (poorer social interactions and poorer work interactions for those caregivers who are employed) while controlling for caregiver age and gender.

This study adds to the existing body of literature on caregivers and sleep by examining a population of unique caregivers who may experience similar disruption in their lives after a family member’s unforeseen diagnosis of a PMBT. Examining what characteristics (e.g., anxiety, burden, comorbidities, care recipient functioning) lead to sleep loss for caregivers of those with PMBTs and how poor sleep affects the health of these caregivers (physical, cognitive/behavioral, emotional, and social) may facilitate the design of interventions in this population.

CHAPTER II

REVIEW OF THE LITERATURE

This chapter provides an overview of the literature regarding PMBTs, responses to informal caregiving, the effects of providing care on caregiver health and sleep, and more specifically, what is known about caregivers of those with PMBTs and sleep. A brief review of the effects of sleep loss on physical and mental health; measurements of sleep and sleep loss; and a discussion of the relationships between stress, depression, sleep loss, and health outcomes are discussed. Gaps in the literature are identified.

Primary Malignant Brain Tumors

The American Cancer Society (ACS; 2010) estimated that 22,020 malignant tumors of the brain and spinal cord were diagnosed in the United States in 2009 and of those diagnosed, approximately 13,140 died. These brain and spinal tumors account for 1.5% of all cancers and 2.3% of all cancer deaths (ACS, 2010). Of those diagnosed with malignant brain and spinal cord tumors in 2010, 14,555 were a glioblastoma, the most common PMBT (ACS, 2010). The average age at diagnosis for glioblastoma multiforme (GBM), a Stage IV malignant glioma, is 64 years (Central Brain Tumor Registry of the United States [CBTRUS], 2010). GBM is the PMBT found in adults over the age of 20, with greater incidences occurring after the age of 65 (ACS, 2010; CBTRUS, 2010). GBM is associated with a poor prognosis; average survival is 14 months after diagnosis (Omay & Vogelbaum, 2009). As the elderly population is increasing faster than any other age group, the incidence of GBM in adults also has increased (up from 13,000 in 2009;

CBTRUS, 2010) and continues to rise (de Robles & Cairncross, 2008; Iwamoto, Reiner, Panageas, Elkin, & Abrey, 2008).

At time of diagnosis, many patients with PMBTs experience memory loss (35%), cognitive changes (34%), motor deficits (33%), language deficits (32%), seizures (32%), personality changes (23%), visual disturbances (22%), and changes in level of consciousness (16%; Chandana et al., 2008). With these functional disabilities already present at time of diagnoses coupled with the changing dynamics of health care delivery into the outpatient setting, the care of the person diagnosed with a PMBT usually becomes the concern and responsibility of the immediate family (Sherwood et al., 2006). Inherent in caring for those with malignant brain tumors, informal caregivers are at increased risks for poor physical and mental health stemming from a variety of pre-existing and situational conditions.

Health Impacts of Family Caregiving

With changes in healthcare delivery and the aging of populations, more families are providing care to members with physical, emotional, and cognitive disabilities (Jansson, Nordberg, & Grafstrom, 2001; Kim & Schulz, 2008). There is extensive literature on the effects of providing care on the caregivers' emotional, physical, social, and financial well-being, defined in the literature as caregiving burden (Braun et al., 2007; Kim & Schulz, 2008; Pinquart & Sorensen, 2003a, 2003b; Van Den Wijngaart et al., 2007; Vitaliano et al., 2003). The chronic stress of providing care is exacerbated by length of caregiving time, degree of care recipient suffering perceived by the caregiver, the unpredictability and uncontrollability of the situation, as well as social and financial stressors (Pinquart & Sorensen, 2003a, 2003b; Vitaliano et al., 2003; Lima, Allen, Goldscheider, & Intrator, 2008). Furthermore, the caregivers’ sense of ability to assume the role and to manage the care necessary for their family member has been shown to negatively affect caregiver health (Schulz & Sherwood, 2008).

The amount of stress (Schulz, O’Brien, Bookwala, & Fleissner, 1995; Wilcox & King, 1999), grief (Schulz & Sherwood, 2008), and depression (Schulz et al., 1995; Wilcox & King, 1999) experienced by caregivers are indices that have been used to quantify caregiver burden. Studies have shown that the greater the care recipients’ disabilities and cognitive impairments, the greater the caregiver depression and mental fatigue (Kim & Schulz, 2008; Nagatomo et al., 1999; Pinquart & Sorensen, 2004). Depression has been noted to be the highest among caregivers of those with dementia as well as in older caregivers, female caregivers, and spousal caregivers (Pinquart & Sorensen, 2003a, 2003b; Schulz & Sherwood, 2008). Socially isolated caregivers, especially spousal caregivers, experienced a marked increase in depressive symptoms when compared to women not providing spousal care responsibilities over time (OR 11.8, 95% CI 4.8, 28.9; Cannuscio et al., 2004).

Grief during the caregiving experience has only been recently studied in the caregiving literature. Grief encompasses the daily losses as well as the inevitable outcome of the caregiving experience (Sanders, Ott, Kelber, & Noonan, 2008; Silverberg, 2006-2007). Stress and its untoward effects on health such as depression, immune function, and cardiovascular function and health habits such as smoking, alcohol use, or sleep have been studied (Pinquart & Sorensen, 2003a, 2003b; Schulz et al., 1995; Schulz & Sherwood, 2008; Vitaliano et al., 2003). Those caregivers who experience more stress have more untoward effects on health. In a landmark study, caregiving has even been associated with increased caregiver mortality (Schulz & Beach, 1999).

Within the emotional context of these situational demands, caregivers must perform complex medical interventions, make decisions, solve problems, supervise the care recipient, and coordinate care. Many assist with ADLs (e.g., grooming, feeding) as well as instrumental activities of daily living (IADLs; e.g., providing transportation, grocery shopping, doing laundry; Given, Sherwood, & Given, 2008). The situational demands are greater in those with cognitive impairments; when caregiving skill demands change as the disease progresses; and when the care recipient's condition deteriorates, especially near the end of life (Given et al., 2008; Pinquart & Sorensen, 2003a, 2003b; Vitaliano et al., 2003).

In the last 15 years, the literature has focused on the effects or outcomes for providing care in a variety of caregiving situations. Schulz et al. (1995) reviewed 41 manuscripts of caregivers of those with dementia because research has shown these caregivers to be the most stressed. Psychiatric symptoms reported in these reviewed caregiver manuscripts included depressive symptoms in up to 39% of caregivers and anxiety in 35.4% of the caregivers. Furthermore, in a comparison between caregivers and noncaregivers of ages over 65, 18% of the caregivers met criteria for a depressive disorder, whereas none of the noncaregivers did. Similarly, none of the comparison subjects met criteria for an anxiety disorder, while 9% of the caregivers did.

Thompson, Fan, Unutzer, and Katon (2008) found more depressive symptoms and anxiety in the disabled elderly population as well. Caregivers developed depressive symptoms at twice the rate of noncaregivers and were significantly more likely to meet the criteria for an anxiety disorder. Family caregivers who experienced work inflexibility reported more depressive symptoms ($\beta = .29$, $p < .05$), whereas family caregivers with full-time employment ($\beta = .25$, $p < .01$) and more difficulty reconciling work and caregiving roles ($\beta = .36$, $p < .01$) reported significantly more role strain than caregivers working part-time or who were unemployed (Wang, Shyu, Chen & Yang, 2010). Strained caregivers ($n = 179$), those who provided more ADLs, more IADLs, and spent more time providing care than caregivers who were less strained ($n = 213$) or noncaregivers ($n = 472$), reported more depressive symptoms, exhibited higher levels of anxiety, and reported inadequate time for sleep, self-care, and other health related activities (Schulz et al., 1997).

Poorer health status in caregivers has been associated with low financial adequacy, high psychological distress, high levels of cognitive impairment in the care recipient (Schulz et al., 1995), difficulty in providing care, recipient need for higher intensity of care, older age, marital status (married), educational background (less than 12 years of education; Navaie-Waliser et al., 2002) and heightened stress (Campbell, 2009). Of caregivers ($N = 1002$), caregivers who were providing high intensity care ($n = 383$) believed that their physical health suffered as a result of caregiving (Navaie-Waliser et al., 2002). In a correlational study, Caswell et al. (2003) found that chronic stress in caregivers of spouses with Alzheimer’s disease ($N = 44$) was associated with impaired memory, attention, and concentration. Other negative health effects experienced by caregivers may be associated with (a) financial stress and strain (Hanratty, Holland, Jacoby & Whitehead, 2007), (b) negative changes in social support (Phillips & Crist, 2008), and (c) with patient decline or anticipatory bereavement (Schulz et al., 1995). In a study of 356 caregivers, Higginson and Priest (1996) found that predictors of family anxiety in the weeks before bereavement included (a) being the spouse of the patient, (b) being a younger patient age, (c) having a shorter time from diagnosis, and (d) having low patient mobility.

In their meta-analysis of caregiver physical health of those caring for persons with dementia (176 studies), Pinquart and Sorensen (2007) found that poorer physical health was associated with older age, not being a spouse, co-residency, higher levels of behavior problems and cognitive impairments in the care recipient, fewer caregiving tasks, longer time in the caregiver role, lower educational levels, lower income, receipt of less informal support, and higher levels of burden and depression. In contrast, in their study of caregivers of those with dementia ($N = 107$), Shaw et al. (1997) found no significant difference between 150 spousal caregivers and married controls ($n = 46$) with regard to health events such as extended illness, unhealthy rating by a nurse, or hospitalization. However, there was a trend for more serious illness in the caregivers ($X^2 = 3.13$, $p = .08$). This serious illness was associated with providing more ADLs ($X^2 = 3.83$, $p = .05$) than with problem behaviors (Shaw et al., 1997). The authors hypothesized that there was a reluctance for caregivers of those with problematic behaviors to leave their spouses alone and schedule necessary medical care, which could have further implications for long-term health (Shaw et al., 1997). Pinquart and Sorensen (2007) recommended longitudinal studies of the caregiving trajectory because the timing of symptoms appears to affect the health trajectory of caregivers, especially as feeling depressed was more strongly associated with caregiver physical health than the actual levels of caregiver demand.

Van Ryn et al. (2011) theorized that a large group of informal caregivers may be at risk for serious health and social consequences due to their cancer care burden. In their study of 677 caregivers of those with colorectal and lung cancer, the researchers found (a) 49% of the caregivers were working for pay; (b) 21% reported poor or fair health, and (c) 21% provided care for other individuals while watching for treatment side effects (68%), managing medication administration (29%), and changing dressings (19%). Caring for persons with PMBTs was similar to other caregiving situations as caregivers of persons with PMBTs perform ADLs for the care recipient, manage disease and treatment effects, and are challenged by memory and behavior changes, which were associated with worse caregiver outcomes (Sherwood et al., 2006). However, caring for a person with a PMBT differs from some other caregiving situations in that the diagnosis is sudden in onset and the illness often progresses rapidly (Armstrong, 2009).

Caregiving for Persons with PMBTs

Like other family caregivers, caregivers of those with PMBTs experience significant caregiver burden similar to those caring for patients with dementia (Schubart et al., 2008; Van Den Wijngaart et al., 2007). This burden for caregivers of those with PMBTs has been quantified in qualitative and descriptive studies to date through stories of distress and measures of depression, stress, and economic hardship (Bradley et al., 2009; Cashman et al., 2007; Keir et al., 2006; Locke et al., 2008; Muñoz et al., 2008; Salander & Spetz, 2002; Schmer, Ward-Smith, Latham, & Salacz, 2008; Sherwood et al., 2004; Sherwood et al., 2006; Sherwood et al., 2007; Sherwood et al., 2008; Wideheim et al., 2002). Sherwood et al. (2006) found that, like with other caregivers, the greater the dependence of the care recipient with a brain tumor on the caregiver, the greater the caregiver burden—particularly because of cognitive impairments and neuropsychiatric symptoms. Caregivers in the studies of patients with PMBTs were predominantly Caucasian females who provided care for less than 3 years of time, most 6 months or less, and were studied at different points in the treatment trajectory. Many were spouses (ranging from 50 to 87% of the study groups) and of varying ages (21-81 years, mean of 51 years; Cashman et al., 2007; Keir et al., 2006; Muñoz et al., 2008; Salander & Spetz, 2002; Schmer et al., 2008; Sherwood et al., 2004; Sherwood et al., 2006; Sherwood et al., 2007; Wideheim et al., 2002).

In their study of 95 caregivers, Sherwood et al. (2006) reported that care recipient neuropsychiatric symptoms are the most difficult to handle for caregivers—the most common symptoms being dysphoria/depression, irritability/lability, night-time disturbances in the form of awakening the caregiver in the night, rising too early in the morning or taking excessive naps during the day, and apathy/indifference. In their qualitative study, Wideheim et al. (2002) found that caregivers acknowledged that they lived with constant fear and anxiety of losing the patient, fear of suffering and death, and uncertainty of the future. This worry and anxiety made concentration difficult.

In their study of 60 caregivers, Keir et al. (2006) used the Perceived Stress Scale (PSS-10) to measure caregiver stress and found higher levels of stress in caregivers especially in younger well-educated caregivers of those with low-grade tumors. In Cohen Karmarck, and Mermelstein’s (1983) study using the PSS-10, the average stress reported for males in the general population was 12.1 and for females, 13.7. In comparison, Keir et al.’s mean PSS-10 average scores for men were higher (17, range 10 - 26, *SD* = 4.66) than for women (17.4, range 4 - 32, *SD* = 6.44). Whether these higher scores were statistically different from stress scores in the general population was not tested. Keir et al. raised the concern of how these stressed caregivers are called upon to make decisions regarding the care of the care recipient because of the care recipient's functional, cognitive, and psychological deficits.

Through qualitative studies, researchers (Cashman et al., 2007; Schmer et al., 2008; Schubart et al., 2008) found that caregivers must provide emotional support to the patient despite the caregivers' personal feelings of distress resulting from intense pressure to (a) juggle roles, (b) battle fatigue, and (c) face their own sadness and fears for the future. Furthermore, caregivers must adapt to the ever changing status of the tumor, leaving the caregivers feeling fearful, anxious, and apprehensive even with social support. Using a grounded theory approach, Sherwood et al. (2004) found that caregivers (*N* = 62) appreciated social support but some had trouble asking for it. In their qualitative study of five family members, Wideheim et al. (2002) found that caregivers were aware of the need for other self-care support through eating properly and getting enough sleep; however, whether this was occurring was not explored.

Within the population of caregivers of those with PMBTs is a select population who are caring for persons with malignant gliomas. These brain tumors are known for their aggressiveness (survival rate of 12 months from diagnosis) and propensity for those of older age (65 years and older; Krex et al., 2007). For the patient who is 70 years of age or older, the survival time is 6 months or less (de Robles & Cairncross, 2008; Iwamoto et al., 2008). There is very little research in this select population. Muñoz et al. (2008) looked at the QOL in patients (*N* = 20) and caregivers (*N* = 17) living with malignant gliomas; however, these patients were high functioning and early in the treatment trajectory. Even at this early stage, Muñoz et al. (2008) noted that the number one physical complaint by caregivers was less restful sleep. Conditions contributing to this poor sleep quality were not the focus of their study.

Impaired Sleep as a Result of Informal Caregiving

Common to caregivers are sleep disorders which have been shown to worsen physical and psychological problems (Perrin et al., 2008, Wilcox & King, 1999). For caregivers, interruptions in optimal sleep are multifactorial (Brummett et al. 2006; McCurry et al., 2007). Interruptions in caregiver sleep routines can be secondary to physiological effects, emotional effects, and caregiving functional effects. There are distinct physiological effects of aging (McCurry et al., 2007) and physical health status because of comorbidities and medications for such conditions (McCurry et al., 2007; Vaz Fragoso & Gill, 2007).

In an extensive review of the literature of caregivers of persons with cancer, Berger et al. (2005) found several caregiver characteristics to be consistently associated with impaired sleep. These characteristics included age, gender, and presence of comorbidities. Although older age is associated with poorer quality of sleep (Fonareva, Amen, Zajdel, Ellingson, & Oken, 2011; Kochar et al., 2007; McCurry et al., 2007), comorbidities may play a more important role in sleep disturbances (Berger et al., 2005). Women report poorer sleep than men (Berger et al., 2005). Other caregiver characteristics affecting sleep include poor sleep hygiene such as irregular sleep/wake schedules and prolonged naps, caffeine and alcohol intake, and smoking (Berger et al., 2005). The sleep environment may affect sleep through excess light, noise, and other stimuli (Berger et al., 2005). Other physical effects can be a result of sedentary lifestyle, social isolation, and limited health promotion time (McCurry et al., 2007). Fonareva et al. (2011) found that sleep architecture differs between caregivers of persons with dementia and noncaregivers when using home polysomnography (PSG). The groups differed on (a) Stage 1 sleep, *F*(1,37) = 4.56, *p* = .04, (b) REM sleep, *F*(1,37) = 5.16, *p* = .03, and (c) sleep latency, *F*(1,37) = 4.56, *p* = .04, with the caregivers spending more time in Stage 1 sleep, less time in REM sleep, and taking longer to fall asleep.

Psychological conditions that may affect sleep include depression and anxiety, stress and poor coping, and loneliness and poor social support (Berger et al., 2005). Fragmented sleep has been shown to have effects on cognition in healthy populations (Cole & Richards, 2005); however, this effect has not been studied in the caregiving literature. Other researchers have noted that caregiver burden and depression, worry, anxiety or cognitive arousal, and bereavement (i.e., emotional distress) all have a detrimental influence on sleep (Brummett et al., 2006; Edell-Gustafsson, Gustavsson, & Uhlin, 2003; Kelly, 2003; McCurry et al., 2007; Vaz Fragoso & Gill, 2007). McCurry et al. (2007) noted that anxiety and depression lead to insomnia and that worry or intrusive thoughts and cognitive arousal interrupt sleep even after the caregiver situation has ended. Cognitive anxiety influenced difficulty falling asleep and sleep quality in 15% of 145 chronically ill patients (Edell-Gustafsson et al., 2003). Sleep disturbances attributed to worry may be related to low self-esteem and increased anxiety and stress (Kelly, 2003). With sleep restrictions, Van Dongen, Rogers, and Dinges (2003) postulated that a person gains a sleep debt which has significant effects on sleep latency and behavioral alertness. Sleep debt was defined as the cumulative hours of sleep loss with respect to individual-specific daily sleep need. Caregivers may experience sleep debt due to the demands of the caregiver role.

Negative affect and lack of social support are related to poor sleep quality in dementia caregivers (McCurry et al., 2007). In depressive situations, sleep aids and sedatives show little evidence of being effective; however, psychological interventions have proven to be helpful. Kochar et al. (2007) found that caregivers with depressive symptoms were twice as likely to report sleep disturbances as caregivers without depressive symptoms; *n* = 375) and noncaregivers (*n* = 694) with low levels of depression. Those with depressive symptoms had more difficulty falling asleep and awakened early. Otherwise, the elderly women, ages 69 to 95 (*M* = 81.3, *SD* = 3.7), did not significantly differ for sleep problems defined as trouble falling asleep, trouble staying asleep, and trouble with awakening early.

Unique to caregivers is the disruption of sleep because of care recipient needs. In Brummett et al.'s (2006) study of 175 caregivers and 169 noncaregiver controls, interruptions due to awakenings by the care recipient or sleeping light because of "feelings of being on duty" (p. 223) lead to poor sleep quality due to its effects on negative affect. More negative affect is significantly related to worse sleep quality (p = .001). Erratic daytime activities contribute to sleep disruptions. Wilcox and King (1999) reported that 60% of their sample of women 50 years of age or older (*N* = 90) self-reported care recipient interruptions that occurred 3 or more times per week. These interruptions were associated with poorer overall sleep quality. Like the earlier study, 63% of total caregivers (*N* = 60) self-reported sleep disruptions due to the nocturnal behavior of care recipients (Creese, Bedard, Brazil, & Chambers, 2008). Of the caregivers, 47% reported being awakened 3 or more times per week. The frequency of the nocturnal disruptions were associated with poorer caregiver mental health ($r = -.34$, $p = .009$) and greater number of depressive symptoms ($r = .38$, $p = .003$; Creese et al., 2008).

In a correlational study of 51 cancer caregivers, Carter and Chang (2000) found that 95% of caregivers expressed severe sleep problems, and 57% were experiencing depressive symptoms at a level that would suggest risk for clinical depression. Higher caregiver depression was associated with worse quality of sleep ($r = .70$, $p < .001$), worse habitual sleep efficiency ($r = .54$, $p < .001$), and worse daytime dysfunction ($r = .59$, $p < .001$). These subscales predicted 63.6% of the variance in the depression scales in their final regression model (Carter & Chang, 2000). In nine bereaved caregivers, scores on the Pittsburgh Sleep Quality Index indicated moderate to severe sleep problems ($M = 12$, $SD = 6.2$; Carter, 2005). These caregivers, based on actigraphic measures, experienced mean sleep latencies of 37 minutes (range 0 -120). The American Academy of Sleep Medicine (AASM, 2010) recommends a sleep latency of less than 15 minutes, a sleep duration of more than 7 hours, and a sleep efficiency of 85%. Sleep duration of the nine caregivers in Carter's (2005) study ranged from 1 to 7.5 hours with a mean of 4.3 hours ($SD = 2.2$), while sleep efficiency scores ranged from 27% - 87.5%, with an average of 58.7% ($SD = 18$).

In 35 female Japanese family caregivers over the age of 40, sleep interruptions were more frequent in those with higher blood pressure and worse chronic fatigue although the findings were not statistically significant (Tsukasaki et al., 2006). Of these caregivers, those who were awakened involuntarily (eight out of 11) had the lowest mean scores for mental energy and highest mean scores for sense of fatigue. Tsukasaki et al. (2006) concluded that caregivers who provide care at night suffer from a general sense of fatigue, physical disorders, and reduced mental energy. In a study by Teel and Press (1999) using self-report measures, older caregivers (age > than 70) reported more fatigue, less energy, and more sleep difficulty than older noncaregivers (Wilks's Lambda = .78, *df* = 9,111, *p* = .001). There were no statistical differences between types of caregiving, as the caregivers in this sample cared for family members with dementia, Parkinson's disease, and cancer. In caregivers caring for those receiving palliative care, 28% of the sample (*n* = 37) reported less than 4 hours of sleep per night (Bramwell, MacKenzie, Laschinger, & Cameron, 1995). In a sample of 248 cancer caregivers, Jensen and Given (1991) found that fatigue resulted from both anxiety and performing caring tasks. This fatigue impacted caregivers' daily schedule through low energy levels and napping.

Caregivers in many caring situations experience sleep deprivation and daytime fatigue (Berger et al., 2005; Castro et al., 2009; McCurry et al., 2007; Wilcox & King, 1999). Sleep disruptions have been associated with increased age (Berger et al., 2005; Bliwise, 2005), nocturnal arousals of the care recipient (Brummett et al., 2006; Wilcox & King, 1999), depression (Castro et al., 2009), and poorer QOL (Carter & Chang, 2000). Caregivers who experienced stress while providing care for family members reported poorer quality of sleep when matched with noncaregivers (Berger et al., 2005; McCurry et al., 2007). The caregivers in the study by Castro et al. (2009) reported poorer sleep quality; however, TST and sleep stages as measured by PSG reflected adequate sleep time when compared to noncaregivers.

Rowe, McCrae, Campbell, Benito and Cheng’s (2008) results differed in caregivers of persons with dementia ($n = 31$) and noncaregivers ($n = 102$) than the objective measures of the Castro et al. (2009) study. Caregivers had shorter TSTs ($t = 3.19$, $p = .002$), less sleep efficiency ($t = 4.81$, $p < .001$), took longer to fall asleep ($t = 2.87$, $p = .007$), and although not statistically significant, had more WASO ($t = 1.84$, $p = .07$). Like Castro et al., these caregivers reported poorer sleep quality on self-report measures; however, unique to this study was the finding that caregivers experienced more night-to-night sleep variability than their noncaregiver counterparts (Rowe et al., 2008). Unlike Castro et al., Fonareva et al. (2011) found differences between caregivers ($n = 20$) and noncaregivers ($n = 20$) in sleep architecture from PSG, $F(1, 37) = 2.83$, $p = .03$ (see previous discussion); however, perceived sleep quality was similar from self-report measures.

These differences help to highlight the need for more research regarding (a) quality of sleep for restoration versus the time spent in sleep stages as measured by objective means and (b) the interplay of the perception of sleep quality and actual physical sleep. Brief periodic arousals from sleep, which can occur for caregivers, reduce the restorative power of sleep (Bonnet, 2011). Sleep deprivation effects are cumulative, such that even a mild reduction in sleep per night can, over a period of time, result in significant functional deficits (Simpson & Dinges, 2007). Without sleep to (a) mediate stress, anxiety, and tension and (b) provide individuals with emotional, mental, and physical energy, caregivers may not have the restorative effects of sleep to accomplish the tasks of daily living or cope with stressful life events (Carter, 2005). For caregivers who are still working, commutes and shift work may further interfere with quantity of sleep (Lee, 2003).

Impaired Sleep in Caregivers of Persons with PMBTs

Caregivers of those with PMBTs have reported sleep disturbances (Muñoz et al., 2008; Sherwood et al., 2006; Wideheim et al., 2002). Yet, sleep has not been the focus of any study in the scant literature of caregivers of those with PMBTs. It is unknown what types of disturbances are reported, the antecedents to the sleep disturbances, and if these disturbances impact daily functioning and QOL.

The prevalence of sleep disturbances in those with brain tumors (i.e., the care recipient) are unknown as well; however, the incidence in other cancer patients has been reported ranging from 30 to 88% (Clark, Cunningham, McMillan, Vena & Parker, 2004). Gapstur, Gross, and Ness (2009) reported that patients with brain tumors may experience sleep/wake disturbances, especially if there was damage to the hypothalamus, which results in excessive daytime sleepiness, melatonin and hypocretin secretion defects which result in poor arousal, and damage to the suprachiasmatic nuclei which affects circadian rhythm. Location of the tumor and/or subsequent treatment with radiation may lead to insomnia, excessive daytime sleepiness, and increased nighttime awakenings. Furthermore, unique to the population with PMBTs is the aggressiveness of the disease leading to rapid changes in cognitive, physical, and neuropsychiatric functioning (Sherwood et al., 2004). Those with PMBTs live an average of 14.6 months with chemotherapy (Omay & Vogelbaum, 2009), while those who are 70 years or older at time of diagnosis live an average of 6 months (de Robles & Cairncross, 2008; Iwamoto et al., 2008). Other antecedents to sleep disturbances in caregivers of persons with PMBTs may include (a) age, as most tumors are in the elderly who are most likely being cared for by an older caregiver, (b) gender, as most caregivers are female, (c) sleeping arrangements, as most are spousal caregivers, and (d) other preexisting sleep disturbances prior to the diagnoses of the PMBT.

The Effects of Sleep Loss on Physical and Mental Health

Much is known about the neurochemistry of the brain during sleep; however, it is still unclear why people sleep and what ramifications result from not receiving quality sleep on a regular basis (Beersma, 1998; Van Dongen, Maislin, Mullington, & Dinges, 2003; Van Dongen, Rogers et al., 2003). With periods of sleep loss, mood changes including sleepiness, fatigue, irritability, difficulty concentrating and even disorientation are common (Bonnet, 2011). How a person responds to sleep loss depends on the amount of previous sleep and the amount of interruption. Besides effects on behavior, sleep deprivation can affect task attention, acquisition of newly learned knowledge, and short term memory. Sleep that has been restricted to less than 7 hours a night on a chronic basis leads to cognitive deficits that become progressively worse over time (Banks & Dinges, 2011). Van Dongen, Maislin, et al. (2003) found that those who routinely receive only 4 to 6 hours of sleep a night over 14 days have the same cognitive impairments of individuals who remain awake for 24 to 48 hours. Furthermore, those who have chronic sleep restriction underestimate the degree of neurobehavioral dysfunction induced by the sleep loss (Banks & Dinges, 2011). Chronic sleep restriction affects endocrine and immune functioning, which has been theorized to be the etiology of the increased incidence and risk of medical disorders, health dysfunction, and mortality in those with chronic sleep restriction (Banks & Dinges, 2011).

In the elderly, epidemiologic studies have shown that sleep disturbances increase with age, with some reports of up to 50% in this population reporting disturbances (Ohayon, 2002; Ohayon & Vecchierini, 2005). Polysomnographic studies in the healthy elderly demonstrated that there was a decrease in TST, in the amount of slow-wave sleep, and in sleep efficiency and there was an increase in awakenings after sleep onset (Ancoli-Israel, 2005), although there was not an increase in complaints of poor sleep quality. There is a tendency to shift toward an earlier bedtime and earlier wake-up time with age as well (Monk et al., 2006). Ohayon and Vecchierini (2005) found those elderly with longer sleep durations (9 hours 30 minutes or more) had more physical disease (*OR*: 2.1[1.0- 5.0]) and less physical activity (*OR*: 2.4 [1.2-4.8]), whereas those with short sleep durations (4 hours 30 minutes or less) had cognitive impairments (*OR*: 2.2[1.2-4.2]), poor health (*OR*: 3.6[1.2-10.8]), and obesity (*OR*: 3.6[1.0-13.1]).

Excessive daytime sleepiness is one result of sleep disruption or sleep deprivation. Stepanski, Lamphere, Badia, Zorick and Roth (1984) reported that although TST was significantly correlated with sleepiness, the consolidation of the sleep was more predicative of daytime sleepiness. It is more important to have 6 hours of undisturbed sleep than to have 7 hours of sleep with multiple awakenings from Stage 1 or REM sleep. The number and type of nocturnal arousals also are an important part in the feeling of daytime sleepiness.

Sleep-related complaints are present in 20%-40% of the general population with 3%-10% of the population using substances to facilitate sleep including alcohol (Kunz & Herrmann, 2000). Of those with sleep-related complaints, 10 to 15% have symptoms of insomnia (Summers, Crisostomo, & Stepanski, 2006). Occasional insomnia may affect up to 27% of the general population (Bastien, Vallières, & Morin, 2001). Insomnia is (a)the difficulty in initiating sleep, difficulty in maintaining sleep, or waking up too early, or (b) sleep that is chronically nonrestorative or poor in quality despite the adequate opportunity and circumstances for sleep (Summers et al., 2006). Others experience fragmented sleep due to underlying undiagnosed sleep disorders such as sleep apnea or restless legs, shift work, travel (Roehrs, Carskadon, Dement, & Roth, 2011), or poor practices promoting sleep (sleep hygiene; Stepanski & Wyatt, 2003).

With daytime functioning dependent on sleep, sleep deprivation—especially of REM sleep—led to cognitive impairments, less socialization, higher morbidity, less productivity and higher risk of accidents (Kunz & Herrmann, 2000). Furthermore, chronic insomnia has been shown to result in impaired occupational performance and poorer QOL (Summers et al., 2006). Fragmented sleep seen in shift workers and its effects on the circadian process and REM sleep led to the cognitive sequelae noted in the insomnia literature (Kunz & Herrmann, 2000).

Insomnia, a term that is closely related to sleep disturbance, has been defined as the repeated difficulty with sleep initiation, maintenance, or quality despite adequate time and opportunity for sleep, resulting in some form of daytime impairment (Harvey & Spielman, 2011). However, Hearson and McClement (2007) pointed out that sleep disturbance in caregivers was not the same as insomnia, which may be used interchangeably in the literature. Disturbances are any change in the caregiver's normal sleep pattern while providing care for a family member. The disturbances can be difficulty falling asleep, fragmented or interrupted sleep, difficulty maintaining sleep, awakening too early in the morning, not feeling refreshed after sleep, excessive daytime sleepiness or inability to function in the caregiving role. Furthermore, Hearson and McClement noted that caregivers do not have adequate opportunity to sleep, and even when given the opportunity to sleep, they remain vigilantly attuned and ready to respond to the care recipient.

Sleep Impairment Effects on Immune Functioning

There is a harmonious relationship between sleep/wake and other circadian patterns of the immune system, endocrine system, and thermal system to support the cause and function of sleep. The cellular components of the immune system such as eosinophils, mononuclear cells, lymphocytes, T-cells, and B-cells are increased between midnight and 2 a.m. (Moldofsky, 1995). Cytokines, immunological signaling molecules produced by leukocytes and other cells, function bidirectionally to modulate immunity and sleep/wake regulation (Krueger 2008; Motivala & Irwin, 2007). Cytokines are elevated in the presence of infection and have been shown to induce the fever and somnolence associated with the infectious process (Moldofsky, 1995). Furthermore, those who experience sleep deprivation have effects on immunity by poorer antibody response to inoculation with the influenza virus (Motivala & Irwin, 2007) and declines in natural killer cell activity through effects on nonspecific immunity (Moldofsky, 1995).

A variety of physical (inflammation, infection) and psychological (anxiety, depression) stressors are associated with changes in neurohormonal and immune reactions in which many of these changes are mediated through pro-inflammatory cytokines (Aouizerat et al., 2009), particularly the pro-inflammatory cytokines interleukin 1 (IL-1), interleukin 6 (IL-6), and tumor necrosis factor alpha (TNF-α: Krueger, 2008; Motivala & Irwin, 2007). Cytokine levels, in the circulation under normal conditions, peak in the night with progressive decreases towards nadir in the morning (Motivala & Irwin, 2007). Motivala and Irwin (2007) in their review article of sleep and immunity, theorized that cytokines promote inflammatory processes associated with a range of health consequences including cardiovascular disease and exacerbations of autoimmune disorders. These same cytokines also affect sleep through dysregulation (Motivala & Irwin, 2007). IL-1β, IL-6, and TNFα are typically elevated during periods of sleep deprivation and have been associated (a) with many of the symptoms characterized by sleep loss (daytime sleepiness, fatigue, cognitive and motor deficits) or (b) by infection or inflammatory processes (Kapsimalis et al., 2008; Krueger, 2008; Simpson & Dinges, 2007). Leptin and ghrelin, hormones associated with hunger and energy balance, are dysregulated with sleep deprivation, which has been postulated to result in increased appetite resulting in higher body mass indices (Kapsimalis et al., 2008). Elevations in IL-6 have been associated with aging-related sleep problems, cardiovascular complications, and the regulation of insulin secretion (Kapsimalis et al., 2008). See Table 1 for cytokines that are involved in pathological sleep.

TNF-α, a pro-inflammatory cytokine, has been involved in the regulation of neuroprotection, sleep, and depression. In family caregivers (*N* = 103) of those with cancer, caregivers who demonstrated a higher sleep disturbance and morning fatigue had the presence of the TNFα genotype (Aouizerat et al., 2009). In family caregivers of those with Alzheimer's disease (*n* = 64), IL-6 plasma levels, another pro-inflammatory cytokine, were descriptively more elevated than matched controls (1.42 ± 1.52 vs. 0.99 ± 0.86 pg/ml, $p < .06$; Von Kanel et al., 2006)—although significantly different. Furthermore, the caregivers had lower TST (369 ± 70 vs. 393 ± 51 minutes, $p = .049$) and

Table 1

Cytokines Involved in Abnormal Sleep Situations

Sleep situation	Cytokines involved
Sleepiness of acute infections	IL-1β, TNF-α
Sleepiness of chronic illness	TNF-α
Sleep deprivation	IL-1β, TNF-α, IL-6, leptin, ghrelin
Obstructive sleep apnea	TNF-α, IL-6
Chronic insomnia	TNF-α, IL-6
Aging-related sleep problems	IL-6
Alcohol-related sleep disturbance	TNF-α, IL-6
Depression	IL-1, IL-2, Il-6, TNF-α
Narcolepsy	TNF-α, IL-6

Note. Adapted from "Cytokines and pathological sleep," by Kapismalis et al., 2008, *Sleep Medicine, 9*, 604.

sleep efficiency (77 ± 11 vs. 82 ± 9%, p = .04). The IL-6 elevation was predicted by WASO (ΔR^2 .039, $\beta = .203$, $p = .04$) and apnea hypopnea index (ΔR^2 .054, $\beta = .252$, $p = .01$), i.e., poor sleep, and has been implicated in risk for greater cardiovascular events (Von Kanel et al., 2006).

In a review of the current literature on cytokines and their effects on sleep and host defenses, IL-1, another cytokine, has been elevated during sleep deprivation and it, with the other pro-inflammatory cytokines, appeared to impact the functioning of the host defenses (Benca & Quintans, 1997). In viral response studies, those who experienced brief periods of sleep deprivation (4 hours for four nights) had a poorer antibody response to exposure to the flu vaccine (Motivala & Irwin, 2007). In an examination of sleep debt, Prather et al. (2009) found that sleep debt scores predicted greater production of IL-1β and IL-6. Furthermore, partial or total sleep deprivation resulted in increased production of IL-6 and TNF-α, raising concerns as too little cytokine production leaves the host vulnerable to infection; however, too much production can lead to the risk of inflammatory diseases (Prather et al., 2009). Further research of cytokine elevations in caregivers who experience sleep losses is needed to understand the implications of the effects of pro-inflammatory cytokines on the immune and sleep/wake systems, both acutely and chronically.

Measures of Sleep in Caregivers

Measurement of sleep can be obtained through objective and subjective measures and ideally accomplished using both methodologies. However, cost, time, type of information to be collected, and invasiveness and intrusiveness to life circumstances are considered when selecting measures.

Objective Measures

The gold standard of objective measurement of sleep is PSG, which can detect the stages of sleep via the electrical activity of the brain (Kushida et al., 2005). This test can be performed in a sleep laboratory or in the home with portable PSG with a technician for lead placement and a clinician for interpretation (Kushida et al., 2005). PSG can detect sleep deprivation via length of slow wave sleep and types of sleep cycles encountered when allowing a person to receive sleep (Bonnet, 2011); however, this is not a very feasible option for research in caregivers due to burden, which has led to small sample sizes in the current literature. Home PSG has recently become popular in the caregiver sleep research, with Castro et al. (2009) exploring it’s feasibility in nine caregivers of those with dementia. In another study, Fonareva et al. (2011) used home PSG in caregivers of those with dementia (*N* = 20).

An actigraph is a sensor that records rest/activity data for up to 2 weeks continuously (Summers et al., 2006). It is presumed that when the person is quiet and without movement, that the person is sleeping. However, there are obvious limitations because the person could be lying still while thinking or could remove the sensor. Newer sensors have skin temperature readings that help discern whether the sensor has been removed or not. Actigraphy can identify sleep/wake cycles and be used with those who cannot spend time in a sleep laboratory. However, correlations are stronger if actigraphy is coupled with sleep logs or diaries to account for periods of inactivity (Summers et al., 2006), yet both are dependent upon the participant.

The sensors are typically worn on the wrist or upper forearm, are easy to manage by a research participant, and are a popular alternative to PSG due to its low cost and invasiveness, and ease of monitoring sleep/wake cycles outside of the laboratory setting (Paquet, Kawinska, & Carrier, 2007). Actigraphical measurements have been obtained in caregivers of those with cancer (Carter, 2006; Carter et al., 2009; Gibbons et al., 2009), dementia (Rowe et al., 2008), or elderly needing home care (Tsukasaki et al., 2006). Using a rigorous approach for sleep measurement with caregivers, Castro et al. (2009) collected actigraphy data on care recipients (*N* = 9) to compare with home PSG readings of the caregivers to confirm if care recipient arousals were impacting caregiver sleep.

Subjective Measures

The Pittsburgh Sleep Quality Index (PSQI) is a self-rated questionnaire developed to discriminate between good and poor sleepers and measure sleep quality during the previous month (Buysee, Reynolds, Monk, Berman, & Kupfer, 1989). This reliable and valid tool (Backhaus, Junghanns, Broocks, Riemann, & Hohagen, 2002; Carpenter & Andrykowski, 1998; Cole et al., 2006; Grandner, Kripke, Yoon, & Youngstedt, 2006; Hayashino, Yamazaki, Takegami, Nakayama, & Sokejima, 2010) takes 5 to 10 minutes to complete, requires no training to administer or score, and produces a global score (0-21). Scores on the PSQI greater than 5 are suggestive of significant sleep disturbance (Buysee et al., 1989). This measure has been used in caregivers of those with dementia (Brummett et al., 2006; Creese et al., 2008; Fonareva et al., 2011; McCurry et al., 1998; Wilcox & King, 1999) and cancer (Carter, 2005; Carter, 2006; Carter & Chang, 2000; Carter et al., 2009).

The Epworth Sleepiness Scale (ESS) is a measure of a person's general level of sleepiness, which is independent of short-term variations in sleepiness, time of day, and from day to day (Johns, 1991). This measure assumes that daytime sleepiness is more of a trait component or a steady and constant aspect of the person (Curcio et al., Bertini, 2001). The ESS does not distinguish between long-term variables impacting sleep, such as sleep deprivation, time of day, sleep disorders, drug effects, situational effects, or physiological issues. Rather, the ESS assumes that an individual can remember whether or not and under what circumstances they have dozed off during a typical day in recent times such as sitting and reading, watching TV, or in a car stopped for a few minutes for traffic. Scores of 16 or greater are associated with greater sleep propensity. The ESS has been used to study sleep in caregivers of those with dementia (Castro et al., 2009; Fonareva et al., 2011; Rowe et al., 2008) and cancer (Gibbins et al., 2009).

Sleep diaries or sleep logs can provide subjective estimates of daytime naps, sleep aids intake, sleep onset latency, frequency of nocturnal awakenings, awakenings duration, wake-up time, arising time, feeling upon arising, and sleep quality (depending on the design; Bastien et al., 2001; Summers et al., 2006). Correlations between the sleep diaries/logs and objective findings are modest to poor as there is a tendency to underestimate TST and overestimate sleep latency by caregivers (Summers et al., 2006). Sleep logs can be used (a) to determine patient perceptions of sleep disturbances rather than quantify sleep abnormalities and (b) in identifying behaviors to which persons tend to adapt, which perpetuate poor sleep quality (Summers et al., 2006). Behaviors can include daytime napping; variable bedtimes; use of products that contain alcohol, caffeine or nicotine prior to sleep; engagement in activities that are stimulating prior to sleep initiation; use of the bed for activities other than sleeping or sexual activity; and an uncomfortable sleeping environment. Diaries have been used as the primary sleep measure in sleep studies of caregivers of those with dementia (Castro et al., 2009; McCrae, Tierney, & McNamara, 2005; McCurry et al., 1998; Willette-Murphy, Todero, & Yeaworth, 2006) and cancer (Carter, 2006; Carter et al., 2009) or as supplement to actigraphy to aid in the interpretation of the actigraphical results.

Some studies did not use a formal sleep assessment measurement but rather open-ended questions about sleep and the caregiving situation (Kochar et al., 2007). Others used a visual analog scale to measure the previous night’s sleep (Teel & Press, 1999). This discussion of sleep measures highlights some of the difficulties in comparing sleep deprivations and disruptions studies because of the variability of measurements and sample sizes across caregiver studies. Many of the early caregiver sleep studies used self-report measures only. Not until around 2005 does the use of objective measures to triangulate with subjective measures appear in the caregiving sleep literature. There remains conflicting information between objective and subjective findings within these studies as well as across the studies. This disparity makes it difficult to tease out the conditions that create sleep loss and its effects on caregiver physical, cognitive/behavioral, emotional and social health.

Relationships Between Stress, Depression, Sleep Loss, and Health Outcomes

Given the complex physiology and interactions within the human body, it is difficult to pinpoint one component that leads to caregiver distress and burden when caring for a loved one with an terminal and cognitively challenging disease process. Stress, depression, and sleep loss are intertwined when examining the impacts on caregiver health outcomes—physiologically, cognitively/behaviorally, emotionally and socially. Causality and directionality are a challenge to discern.

Stress has been linked to sleep disturbances in the form of ruminations at bedtime (Akerstedt, Perski, & Kecklund, 2011). This has led to reports of increased sleep latencies and sleep efficiencies following periods of stress. The effects of stress and sleep loss are similar in their actions on the endocrine/metabolic systems. Both stress and sleep loss increase the levels of cortisol, lipids, and insulin resistance—physiological changes that have been linked to increased cardiovascular disease and Type II diabetes. In normal sleep, there is increase in growth hormone (GH) and suppression of those hormones associated with hypothalamic-pituitary-adrenocortical (HPA) axis, a key pathway in stress response that releases neuropeptides that result in sympathetic activation. With the increase in cortisol production, there is a subsequent increase in sleep fragmentation secondary to micorarousals. With the reduction of GH, there is less SWS seen in the early cycles of sleep. Stress has been linked to increased complaints of fatigue, cognitive impairments, and negative mood. Sleep is considered one of the means of restoring the body to a less stressed state (Akerstedt et al., 2011).

Subjective sleep complaints, including longer sleep latency, more frequent and longer awakenings, shorter TST and earlier morning awakening, are hallmark symptoms in persons with depression (Mayers, Grabau, Campbell, & Baldwin, 2009; Peterson & Benca, 2011) and have been confirmed by PSG (Sculthorp & Douglass, 2010). It is unclear whether some of the sleep abnormalities predate the development of depression and indicate a vulnerability to it or if some of the sleep disruptions are features that are only present during depressive episodes (Sculthorpe & Douglass, 2010). Dysregulation of the HPA axis that mediates the neuroendocrine stress response has been consistently correlated with depression. Similar to that of sleep and stress, depression also decreases SWS; however, there is also abnormality of REM as seen with PSG (Peterson & Benca, 2011), which has been implicated in the maintenance of negative emotional stimuli (Walker, 2009). This REM abnormality may have implications for the poorer perception of sleep quality in the presence of adequate sleep time found by Mayers et al. (2009) in their study of sleep and depression, which differed from the poor sleep timing perceptions by those with anxiety. Other symptoms of depression include fatigue and a diminished ability to think or concentrate, or indecisiveness, which mimic the cognitive impairments seen in sleep deprivation (Peterson & Benca, 2011). Depression is associated with cardiovascular morbidity and mortality (Jiang et al., 2001), and with diabetes (Anderson, Freedland, Clouse, & Lustman, 2001; Robinson, Fuller, & Edmeades, 1988), although these mechanisms are unknown. Robinson, Fuller, and Edmeades (1988) found that diabetics with depression had poorer glycemic control and less social support.

Sleep loss has been implicated in altered immune functioning. (See previous discussion on cytokines.) Furthermore, sleep disruptions have been closely associated with cardiovascular disease, metabolic syndrome (Javaheri, 2011), endocrine disorders such as diabetes and thyroid disease (Grunstein, 2011), gastrointestinal disorders (Orr, 2011), and kidney disease (Unruh & Sanders, 2011). With the intertwining of the neuroendocrine system, immune system, thermal system, and sleep/wake system, it remains difficult to implicate just one system in a cause-and-effect relationship. Yet, it is remarkable that sleep disturbances appear to be a common theme when examining stress, depression, and other comorbidities. For those who care for persons with a PMBT, sleep has not been examined although it is known that these caregivers often are stressed and anxious and many have depressive symptoms.

Summary

Sleep impairments for caregivers are multifactorial and can be secondary to physiological effects, emotional effects, and caregiving functional effects. For those who are caregivers of those with PMBTs, there are no quantifiable sleep measurement studies within the literature. Currently, there is only anecdotal information that caregivers of those with PMBTs have sleep affected by caregiving or anxiety about the terminal situation, with small sample sizes in most of these studies. It is assumed that caregivers of persons with PMBTs are similar to those who care for persons with dementia as cognitive impairments are present at time of diagnosis and both are terminal illnesses. However, the trajectory of a PMBT is of shorter duration than dementia with more rapid deterioration of the health of the care recipient. This shorter trajectory may change how sleep impairments are manifested in this caregiving population.

Research is needed to characterize sleep impairments in caregivers of those with PMBTs using both subjective and objective measures to determine the intrinsic and extrinsic conditions that promote the disturbances, if found. Relationships between sleep quality, time spent in rest and activity, and QOL would be useful in designing interventions to assist this population of caregivers. This study addressed these gaps by using a large sample size (> 150), by using objective and subjective measures of sleep, and by examining subjective and physiologic measures that are proposed to be associated with sleep loss.

CHAPTER III

METHODOLOGY

This chapter describes the research design. Descriptions of the sample and instruments are included. A discussion of the analysis plan for the study is provided.

Research Design

This secondary data analysis was a descriptive correlational design using baseline data from a larger study of mind-body interactions in family caregivers of those with the neuro-oncology disorder of a PMBT (*Mind-Body Interactions in Neuro-Oncology Caregivers*, National Cancer Institute R01 [CA118711-02] Sherwood, PI, 2007). The parent study was a descriptive longitudinal study to identify the interrelationships between disease characteristics, personal characteristics, psycho-behavioral responses, biologic responses, and overall physical health in an inception cohort of caregivers for persons with PMBTs throughout the first year of the care trajectory.

In this secondary analysis, I examined (a) relationships among caregiver personal characteristics; (b) variables associated with sleep deprivation and disruption, and sleep loss; and (c) caregiver physiological, cognitive/behavioral, and emotional and social health outcomes. Also, I analyzed baseline data for those caregivers and care recipients enrolled from October 1, 2005 through April 30, 2011. The parent study was approved by the Institutional Review Board at the University of Pittsburgh, the site of data collection, and the secondary data analysis study was approved by Georgia State University, the site of data analysis. Data collection included standard questionnaires, serum blood draw for cytokine levels, and sleep/activity data for 3 days using an accelerometer device worn on the arm. A detailed description of instruments is provided later.

Participants and Setting

Caregiver participants and their respective care recipients were approached for consent in the neuro-oncology and neurosurgery clinics at an urban tertiary medical center after the identification of a PMBT. Care recipients designated caregivers by the care recipient as the person who would be providing the majority of support: emotionally, financially, and physically. Caregivers did not have to be legally related to or live with the care recipient. Both members of the dyad had to consent in order to participate in the parent study.

Eligibility criteria for caregivers from the parent grant included: (a) 21 years of age or older; (b) were able to read, write, and understand English; (c) had access to a telephone; (d) were not the primary caregiver for anyone else other than children under 21; (e) were not paid for their care; and (f) gave written informed consent. The exclusion of those less than 21 years of age was decided by the parent study researchers due to the rarity of persons under the age of 21 caring for an adult with a PMBT. The sample consisted of 133 caregiver-care recipient dyads.

Care recipients were eligible for the parent study if they (a) had an identified PMBT within the last month via pathology report, (b) were 21 years or older, (c) were able to read, write, and understand English, and (d) gave written informed consent.

Instruments

Variable measurement in this study involved both objective and subjective measures. The sleep variables of TST and WASO were measured using accelerometers, while serum blood levels of ILs were measured by an outside laboratory after being drawn by trained research assistants. All other variables were measured with self-report instruments (see Appendix A).Adverse Caregiver

Outcomes Related to Sleep Loss

Adverse caregiver outcomes related to sleep were measured. The health outcomes were separated into four dimensions (physiological, cognitive/behavioral, emotional, and social). Each dimension had its own specific measures as discussed below; however, an overall health outcome was not examined.

Physiological dimension. For caregiver physiological outcomes, immune function and physical health were measured. After consent, trained registered nurses drew serum blood for testing. The blood was then tested for immune system function: IL-1 receptor antagonist (IL-1ra) and IL-6 levels, cytokines that have been associated with inflammation, poor sleep, and subsequent effects on the immune, cardiovascular, and neuroendocrine systems (Aouizerat et al., 2009; Benca & Quintans, 1997; Ovaskainen et al., 2009; Von Kanel et al., 2006). IL-1 and IL-6 levels peak in the night and progressively decrease until nadir in the morning (Motivala & Irwin, 2007). Interleukin-1ra has been used as a proxy for IL-1β as both cytokines are secreted in response to physiological or psychological stress; however, IL-1ra levels remain elevated in the serum longer (Milaneschi et al., 2009). IL-1β is a pro-inflammatory cytokine which initiates an immune response to insult, whereas IL-1ra is an anti-inflammatory cytokine released to modulate IL-1β activity and return the immune system to homeostasis (Frey, Fleshner, & Wright, 2007; Lehto, et al., 2010). Elevations of IL-1ra and IL-6 during daytime draws were presumed as dysfunction of the immune/inflammatory system and high risk for poor physical health. IL-1ra levels range from 0-500 pg/mL, and IL-6 levels range from 0 to 0.5 pg/mL (ARUP Laboratories, 2011). Serum blood results were treated as a continuous variable for analysis purpose. The average of the inter- and intra-assay coefficients of variation for the concentration range of IL-1ra and IL-6 were examined, and those caregivers with results higher than 20% were not used as they indicated the presence of infection. The Behavioral Immunology Laboratory at the University of Pittsburgh performed the immunoassays and controls using standard protocols.

Physical health was measured using the physical health component of the Medical Outcomes Study short form (MOS SF-36). The MOS SF-36 is a valid and reliable health survey with 36 questions that has been used extensively (McHorney, Ware, Lu, & Sherbourne, 1994; McHorney, Ware, & Raczek, 1993). The survey comprises eight scales (physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health). The eight scales then aggregate into two summary measures of physical health (physical functioning, role-physical, bodily pain, and general health) and mental health (vitality, social functioning, role-emotional, and mental health). Each item is assessed on a Likert-type scale that varies from item to item. Higher scores reflect higher physical and mental health. Most studies using the MOS SF-36 have scale and summary measure reliabilities exceeding .80 (McHorney et al., 1994; Ware, Snow, Kosinski, & Gandek, 1993) while the reliability estimates for the physical and mental health summaries usually exceed .90 (Ware, Kosinski, & Keller, 1994).

Cognitive/behavioral dimension. The cognitive/behavioral domain consisted of measures for caregiver fatigue and QOL. Caregiver fatigue was measured using the vitality subscale of the MOS SF-36 (previously discussed with physical health). The vitality scale of the MOS SF-36 has four items with higher scores, reflecting feeling full of pep and energy all of the time during the last 4 weeks (whereas a low score reflects feeling tired and worn out all of the time; Ware & Sherbourne, 1992). Reliability alpha coefficients for the vitality scale range from .76 to .88 (McHorney et al., 1994).

Caregiver overall QOL was measured using the Fox Simple Quality of Life Scale (FSQOL; Fox, 2004). The FSQOL, and instrument piloted with cancer patients, is a 25-item instrument designed to measure the cognitive components such as satisfaction and well-being and affective components such as health and functional status of QOL (Fox, 2004). Each item is assessed on a 5-point scale: 1 (*strongly disagree*) to 5 (*strongly agree*) with higher scores reflecting higher QOL. Fox (2004) (a) performed an analysis of structure to assess use of a total scale score (which ranges from 25 to 125), (b) established content validity using a qualitative approach, and (c) assessed construct validity with three other QOL instruments (Cronbach's alphas ranging from 0.80 to 0.91). The FSQOL was internally consistent with a Cronbach's alpha of .93 (N = 144; Fox, 2004).

Emotional dimension. The emotional domain was defined as depressive symptoms and spiritual well-being. Depressive symptoms were measured using the 10-item form of the Center of Epidemiologic Studies-Depression scale (CES-D; Andresen, Malmgren, Carter, & Patrick, 1994)—a shortened version derived from the original 20-item instrument designed to measure depressive symptoms in community populations (Radloff, 1977). Criterion validity for the short form of the CES-D has been established using the full CES-D ($R^2 = .92$; Cheung, Liu, Phil, & Yip, 2007). The short form CES-D is a 10-item instrument with a cut off score of ≥ 10 indicative of possible clinical depression (Andresen et al., 1994). Each item is assessed on a 4-point scale and reflects the frequency that each symptom is experienced in the past week: 0 (*none of the time*) to 3 (*all of the time*). Andresen et al. (1994) found a good predictive accuracy with the 10-item CES-D (kappa = .97, p < .001) and obtained retest correlations of *r* = .71 for 2 weeks and *r* = .59 for 12 months in well older adults. A sensitivity of .96 has been obtained with a specificity of .81, positive predictive value of .44, and negative predictive value of .99 in persons with rheumatoid arthritis (Martens, et al., 2006). Total scores on the 10-item CES-D range from 0 to 30, with higher scores indicating the presence of more depressive symptoms (Martens et al., 2006). Miller, Anton, and Townson (2008) obtained a Cronbach's alpha of .86 with the short form and a test-retest reliability of .85 in patients with spinal cord injury. The MOS SF-36 and a visual analog scale of fatigue were used to establish convergent validity in the spinal injury population (Miller et al., 2008).

Spiritual well-being was measured using the Functional Assessment of Chronic Illness Therapy- Spiritual Well-Being Scale (FACIT-Sp; Peterman, Fitchett, Brady, Hernandez, & Cella, 2002). The FACIT-Sp is a 12-item scale designed to describe aspects of spirituality and/or faith that contribute to QOL with people experiencing chronic and life-threatening illnesses. Emphasis is on sense of meaning in life, harmony, peacefulness, and a sense of strength and comfort from one's faith. Each item is assessed on a 5-point scale for truths about how the person has been feeling over the last 7 days with regard to his or her faith. The scale ranges from 0 (*not at all*) to 4 (*very much*). Total scores range from 0 to 48 with higher scores reflecting a greater sense of peace, meaning, strength, and comfort in one's faith. Convergent validity was established using other measures of spirituality with correlations ranging from .31 to 0.48 ($p < .005$) while the internal consistency reliability for the instrument was .86 (Peterman et al., 2002).

Social dimension. The social domain measure was defined as perceived quality and availability of social support. For those caregivers who were still employed, the quality and ability to interact in the work life was measured as a part of the social dimension. Social support was measured using the Interpersonal Support Evaluation List (ISEL), a 40-item instrument used to examine the perceived availability of social support (Cohen & Hoberman, 1983; Cohen, Mermelstein, Kamarck, & Hoberman, 1985). There are four subscales with 10 items each: (a) tangible, measuring perceived availability of material aid; (b) appraisal, measuring the perceived availability of someone with whom to talk about one’s problems; (c) self-esteem, measuring the perceived availability of a positive comparison when comparing oneself with others; and (d) belonging, measuring the perceived availability of people with whom one can do things (Cohen et al., 1985). An overall score ranges from 0 to 120, with higher scores indicating more perceived social support. Cronbach’s alphas for the whole instrument ranged from .88 to .90, with the subscale alphas ranging from .62 to .82. The ISEL consistently correlates with other measures of stress in a manner that suggests that social support buffers people from the pathogenic effects of stressful events (Cohen, et al., 1985).

Work life interactions were measured using the Work Limitations Questionnaire (WLQ), a 25-item instrument for measuring the impact of chronic health problems and/or treatments on job performance and work productivity (Lerner et al., 2001). Each item is assessed on a 5-point scale rating the frequency of difficulty in performing 25 specific job demands: 1 (*able all of the time*) to 5 (*able none of the time*). The frequency ratings result in four dimensions: handling time (five items with a range of 5 to 25), physical (six items with a range of 6 to 30), mental-interpersonal (nine items with a range of 9 to 45), and output demands (five items with a range of 5 to 25). The item responses can be summed and/or averaged to indicate an estimated percentage of overall productivity loss due to health, or the four scales can be used separately to reflect the amount of limitations in the respective domains of work. Higher scores reflect more productivity loss or limitations. The four subscales have adequate Cronbach's alphas ranging from .88 to .97 in populations with rheumatoid arthritis, chronic daily headache, and epilepsy (Lerner, et al., 2001; Lerner, Reed, Massarotti, Wester, & Burke, 2002). Construct validity was established using the MOS SF-36 role/physical and role/emotional scales (Lerner et al., 2001).

Sleep Loss

Both objective and subjective measures of sleep loss were obtained. Sleep loss was defined as interrupted or shortened sleep times other than the intended amount of TST wanted by the caregiver. Objective sleep loss was determined using two measures: TST and WASO. The first measure was TST, defined as nocturnal sleep time and calculated as the minutes from the first falls-asleep episode to the wake up time (time in bed [TIB]) minus any awake time during the nocturnal sleep time (TST = TIB - total minutes of awake time). A fall-asleep episode is any 30-minute period of sleep or longer after 8 p.m. as recorded by the Bodymedia® Sensewear™ Armband.

The second measure was WASO, which was calculated as (1 - TST/TIB - sleep latency) x 100% (Carter, 2006) using Bodymedia® Sensewear™ Armbands (Bodymedia.com)—accelerometer devices containing 2-axis micro-electro-mechanical sensors that measure motion. These armbands are worn for 24-hour periods and monitor activity, rest, and temperature. The algorithms using acceleration due to gravity can predict whether the armband is being worn, such as when a person is getting in and out of bed or lying down. A heat flux sensor, skin temperature sensor, and near-body ambient temperature sensor collect thermal information as well (Sunseri et al., 2009). The Bodymedia® Sensewear™ Armbands, when compared with polysomnography, are able to predict sleep in slow wave sleep and REM 100% of the time, with true positive predictions of 98.9% in Stage II sleep and 94% in Stage I sleep. The device is limited in detecting wake episodes less than 10 minutes (Sunseri et al., 2009). The armbands were calibrated by trained research assistants prior to participant usage.

Subjective sleep loss was measured by using the sleep quality subscale, a single-item of the PSQI (Buysse et al., 1989) which measures sleep quality and habits in the past month. The PSQI sleep quality subscale uses a 4-point scale ranging from 0 (*very good*) to 3 (*very bad*). Higher scores on the subscale reflect poorer sleep quality (Buysse et al., 1989). The PSQI is a well-established and widely used valid and reliable instrument for measuring sleep quality. The single-item sleep quality subscale had an overall correlation coefficient of .83 when compared with the global score in the original PSQI psychometric testing. In this same pilot study, discriminant validity was established with nondepressed controls who had a correlation coefficient of .64 on the sleep quality subscale while those with known depression had a correlation coefficient of .71 (Buysse et al., 1989). The sleep quality subscale Cronbach’s alphas were .80 in bone marrow transplant patients, .83 in renal transplant patients, .79 in breast cancer patients, and .81 in benign breast problem patients when correlated with the global PSQI score (*p* < .001; Carpenter & Andrykowski, 1998).

Additional Sleep Characteristics

Additional data about sleep characteristics obtained from the accelerometers included sleep efficiency, sleep latency, time of sleep onset, time of sleep completion for the nocturnal sleep period, and naps outside of nocturnal sleep. Sleep efficiency (SE) was calculated as 100% minus WASO (S. Lee, personal communication, August 3, 2011). Sleep latency was defined as the amount of time it takes to fall asleep (Carter, 2006; Motivala & Irwin, 2007) and was calculated as the bedtime when first attempting nocturnal sleep minus the time of nocturnal sleep onset in minutes. Daytime sleep time or naps was any period of sleep between 0900 and 2000 hours. The number of naps and the time for each nap were calculated. Total nap time was TIB Daytime minus total minutes of awake time. Daytime TST was the sum of all nap times in minutes. All calculations were averaged over the nights of collected data. Data from any participant who collected only one night of sleep data were not used in analyses; a minimum of two nights was required. The sleep/wake cycle was determined by the sleep bed time and the wake time of the participant for the day and by examining the relationship among the day’s times for synchronization.

Sleep Deprivation Variables

Variables that contribute to sleep deprivation included caregiver characteristics of age, gender, and employment; sleep/wake cycle; and caregiving demands. Age in years was collected as a continuous variable, gender as a dichotomous variable, and employment status as a categorical variable. Caregiving demands were defined by the caregiver’s response to the care recipient’s symptoms and measured by adapting the M. D. Anderson Symptom Inventory-Brain tumor instrument (MDASI-BT). The MDASI-BT is a 22-item instrument that measures both the neurologic and cancer-related symptoms in those persons with a PMBT. There are six underlying constructs measured: affective, cognitive, focal neurologic deficit, constitutional, generalized symptoms, and a gastrointestinal related item (Armstrong et al., 2006). Each item is rated on an 11-point scale: 0 (*not present*) to 10 (*as bad as you can imagine*). Ratings of 5 or 6 are considered moderate, with ratings of 7 or greater considered as severe.

Construct validity was established with a sample of 201 PMBT patients (Armstrong et al., 2006). A mean of the patient’s ratings for the items is used as a measure of overall symptom distress, with higher means representing higher symptom distress. Cronbach’s alphas for the six constructs ranged from .67 to .91, with an overall internal consistency of 0.91 (Armstrong et al., 2006). In the parent study, the caregiver was asked on the 11-point scale to respond to how much the caregiver was distressed by each of the symptoms listed on the MDASI-BT if present in the care recipient. Item responses were summed for a total score ranging from (0 to 220), with higher scores indicating higher caregiver burden in response to the care recipient’s symptoms. A total bother score was calculated using the number of symptoms present divided by the total summed burden score, with scores ranging from 0 to 11. Higher scores reflected more caregiver bother by the care recipient symptoms.

Care recipient functional status was measured to further reflect caregiver demands based on the care recipient’s ability to perform ADLS as measured by the Karnofsky Performance Scale (KPS; Karnofsky, Abelmann, Craver, & Burchenal, 1948). This scale was developed to assess a patient's ability to carry on normal activities or his or her degree of dependence on help. The scale is divided into increments of 10: 0 (*dead*) to 100 (*normal, no complaints, no evidence of disease*). Scores between 80 and 100 equate to being able to perform normal activity and to work. No special care is needed. Scores between 50 and 70 equate to being unable to work; however, the individual is able to live at home and care for most personal needs with varying amounts of needed assistance. Scores between 10 and 40 equate to being unable to care for one's self and requiring the equivalence of institutional or hospice care usually signaling rapid progression of disease (Karnofsky et al., 1948). Construct validity was established using correlations with other measures of physical ability as well as inter-rater reliability between nurses and family ($r = .66$) in patients with advanced cancer (Yates, Chalmer, & McKegney, 1980). The KPS has been used extensively by cooperative cancer research groups and has been shown to be related to tumor response and survival (Pasacreta, 2004).

Sleep Disruption Variables

Sleep disruption was defined as aspects of the caregiving situation that contribute to fragmented sleep. The variables are caregiver stress, caregiver anxiety, nicotine use, and presence of comorbid conditions of the caregiver. Caregiver stress was measured using the Caregiver Reaction Assessment (CRA) instrument which was designed to systematically assess the primary caregiver situation in the care of persons with physical or mental illness (Given et al., 1992). The CRA is a 24-item instrument that consists of five domains: caregiver's self-esteem, lack of family support, impact on finances, impact on schedule, and impact on health. Items are rated on a 5-point scale, 1 (*strongly agree*) to 5 (*strongly disagree*), with total scores ranging from 24 to 120. High total scores indicate positive reactions to caregiving.

Construct validity of the CRA was assessed through comparisons with other measures of self-perceived pressure from informal care and from measures of impact on social activities (Nijboer, Triemstra, Tempelaar, Sanderman, & Van Den Bos, 1999). Cronbach's alphas for the subscales ranged from .57 to .90 (Given et al., 1992; Grov, Fossa, Tonnessen, & Dahl, 2006; Nijboer et al., 1999). The reliability coefficient for the total CRA ranges from .74 to .79 (Grov et al., 2006; Nijboer et al., 1999). To calculate a total CRA score, which was not originally proposed by Given et al. (1992), the self-esteem scale was reverse coded. The subscales were then summed and divided by the number of questions (Grov et al., 2006). Higher scores indicated a more positive reaction to the caregiving situation.

Caregiver anxiety was measured using the shortened Profile of Mood States-Anxiety scale (POMS-anxiety). The shortened POMS was developed to assess transient distinct mood states (McNair, Lorr, & Droppleman, 1971; Shacham, 1983). The tension-anxiety subscale is a 6-item scale in which items are rated on a 5-point scale: 1 (*never*) to 5 (*always*). The total subscale score ranges from 6 to 30, with higher scores indicating more anxiety. Discriminant validity has been established in cancer patients (Cella et al., 1987). Cronbach's alphas for the tension-anxiety subscale range from .80 to .91 (Baker, Denniston, Zabora, Polland, & Dudley, 2002; Curran, Andrykowski, & Studts, 1995; Shacham, 1983).

Nicotine use was collected as a dichotomous variable as was the presence of caregiver comorbidities such as obesity, hypertension, diabetes, emphysema, and heart problems. Height and weight were collected as continuous variables, which were used to calculate body mass index (BMI, kg/m^2) to evaluate the presence of obesity. The number of comorbidities reported by caregivers were summed to provide an overall health condition score. The higher the score, the more comorbidities present. This approach of summing major comorbidities has been used by others (Clark et al., 2004).

Caregiver and Caregiving Characteristics

General information including ethnicity, racial group, educational level, income, and length of time caring for the care recipient were used to describe the caregivers and the caregiving situation.

Care Recipient Characteristics

Characteristics of the care recipient tumor status were obtained from the medical record whereas other demographical information was obtained through patient interview. Neuro-cognitive testing was collected by trained research assistants along with the assessment of the care recipients' performance of ADLs using the KPS (Karnofsky et al., 1948; as previously discussed).

Data Collection Procedures

Data were collected separately from each member of the dyad by trained members of the research team. Care recipient data were collected from the medical record and by an in-person interview at time of consent. After consent, a blood sample was drawn from caregivers by trained registered nurses before the administration of caregiver questionnaires (see Appendix B). Caregivers were given instructions in the use of Bodymedia® Sensewear™ Armbands, which were given to the caregiver at time of consent (see Appendix C). Caregivers were instructed to wear the Bodymedia®

Sensewear™ Armbands for 3 consecutive 24-hour days. Once data collection was complete, the armband was mailed to the study coordinator in a stamped, self-addressed box. Within 72 hours of the care recipient's interview, caregiver self-report data were collected via a telephone interview by trained research assistants from the parent study using a standardized protocol.

Data Management

Data Analysis

All data were checked for completeness and verified with the parent study researchers if missing variables were identified. The data were analyzed with PASW Statistics 18 for Windows (Version 18.0.0). Frequency distributions and other graphical methods were examined for reasonable approximations to normality for all continuous variables. Kolmogorov-Smirnov and Shapiro-Wilk tests for normality were performed. Missing data between and within a participant were examined to determine whether imputations were needed for analyses. Descriptive statistics were used to describe sample characteristics and major study variables. Pearson's correlation coefficients were used to (a) examine relationships among sleep loss variables, sleep deprivation variables, sleep disruption variables, caregiver and care recipient variables, and adverse health outcome variables; (b) finalize variables to be included in the final models; and (c) identify potential covariates. Covariates identified from the sleep literature included age (sleep disturbances are greater in older persons; Ancoli-Israel, 2005; Berger et al., 2005; Castro et al., 2009; Lee, 2003) and gender (sleep disturbances are greater in women; Berger et al., 2005; Castro et al., 2009; Lee, 2003) and were controlled for when examining the models.

Hierarchical multiple linear regressions were conducted (a) to determine the percent variance contributed to sleep loss variables by caregiver and care recipient variables, sleep deprivation variables, and sleep disruption variables and (b) to determine the percent variance contributed to each individual health outcome (physiologic, cognitive/behavioral, emotional and social) by caregiver and care recipient variables, sleep deprivation variables, sleep disruption variables, and sleep loss variables. The *R* square change for each step were evaluated as was the entire model *F* statistic for significance. Beta's were evaluated to determine the independent predictors of each model. Statistical significance was set at the $p < .05$ level.

For Hypothesis 1: Sleep deprivation (caregiving demands, care recipient physical function, caregiver age, gender, and employment) and sleep disruption (stress, anxiety, nicotine use, and health conditions) will contribute significant variance to sleep loss (TST, WASO, and sleep quality). The first step in the full theoretical hierarchal regression models was to enter the covariates age and gender a priori from the literature. The second step included the rest of the sleep deprivation variables of caregiving demands and employment. The third step included the sleep disruption variables (stress, anxiety, nicotine use, and health conditions). These steps were followed for each of the dependent variables of sleep loss, hence three models were created: one for TST, one for WASO, and one for sleep quality. The R^2 change for each step and the R^2 for the overall models was examined in the analyses.

For Hypothesis 2: Sleep deprivation (caregiving demands, care recipient physical function, caregiver age, gender, and employment), sleep disruption (stress, anxiety, nicotine use, and health conditions), and sleep loss (TST, WASO, and sleep quality) will contribute significant variance to adverse physiological health outcomes (poorer physical health [SF-36] and increased serum blood levels of Interleukin 1 and Interleukin 6), the first step included entering the covariates of age and gender, followed by Step two with the entering of the rest of the sleep deprivation variables of caregiving demands and employment. The third step included the sleep disruption variables (stress, anxiety, nicotine use, and health conditions). These steps were followed when creating the models for the dependent variables of physiological health (altered immune functioning and physical health).

For Hypotheses 3, 4 and 5, the procedure remained the same, with a change in the dependent variables as indicated in each hypothesis. Hypothesis 3 examined variance contributions for the cognitive/behavioral outcomes; Hypothesis 4, emotional outcomes; and Hypothesis 5, social outcomes.

For Research Question 1: What are the sleep patterns (sleep onset times, sleep awake time, TST, WASO, naps, sleep efficiency, sleep/wake cycle) of informal caregivers of those with PMBTs, descriptive statistics and bivariate analysis were used to examine sleep patterns.

Threats to Internal Validity

Instrumental threats to internal validity have been identified and were considered when analyzing the statistical results. The sleep quality subscale of the PSQI was a single-item scale which makes the validity of the measure difficult to ascertain. It was difficult to determine the establishment of content and construct validity as this subscale has not been used as a single measure in other caregiving literature. It is usually calculated as a part of the total PSQI score; however, there is information about the reliability of the subscale in reports using the full PSQI instrument. Furthermore, the Bodymedia® Sensewear™ Armbands (accelerometer) were limited in detecting wake episodes of less than 10 minutes, which could invalidate the WASO and TST measurements obtained. Although WASO could be underestimated with TST, the data were treated with consistency across the participants and with a larger number of participants, statistically this threat should have been minimal. Both of these identified threats, a single-item measure and limited detection of short awake periods, influenced the sleep loss variable. Other additional measures of sleep were compared to these results to ascertain if these threats compromised the results. Other measures included the participants' reported usual sleep patterns, usual bedtime, usual arousal time, and so forth.

CHAPTER IV

RESULTS

The results of this descriptive, correlational study regarding sleep loss and its health effects among caregivers of those with PMBTs are presented in this chapter. Descriptions of the sample characteristics from this secondary data analysis, findings from the measurements used in this sample, and results of hypotheses testing and of the research question are reported.

Between October 1, 2005 and April 30, 2011, 155 caregivers and care recipients were enrolled in the mind-body parent study in a mid-size urban city at a midwest neuro-oncology clinic. Of the 155 caregivers, 22 dyads did not complete the baseline data instruments (14% attrition rate). If the care recipient declined to continue in the study, both caregiver and care recipient were removed from the study. The care recipients in this attrition group were predominantly male (68%, $n = 15$), with a mean age of 62 years ($SD = 18.4$), and a high percentage (63%) of occurrence of high grade PMBTs. The care recipients who dropped out of the study did not differ from those remaining in the study on characteristics of (a) gender, $\chi^2(1) = .87$, $p = .35$; (b) education, $t(12) = .57$, $p = .58$; (c) tumor type, $\chi^2(2) = .15$, $p = .92$; and (d) physical functioning, $t(116) = .37$, $p = .71$. However, the care recipients who dropped out of the study were significantly older ($M = 62.1$, SD 18.4) than those in the study ($M = 53.3$, SD 13.9), $t(144) = 2.24$, $p = .03$.

Sample Characteristics

The final sample included 133 primary family caregivers and care recipients. The care recipients were predominantly middle aged males with a Grade IV malignant glioma (glioblastoma multiforme) who were White, married with a spousal caregiver, and well educated. The care recipients were high functioning physicaly, with 39.1% (*n* = 52) reporting no complaints or minor symptoms. Approximately 19% (*n* = 25) reported some symptoms requiring minimal assistance with IADLs, 9% needed assistance with ADLs (*n* = 12), and 11.2% (*n* = 15) required considerable assistance or were unable to carry on normal activity (see Table 2).

Table 2

Care Recipient Characteristics

Characteristic	*n*	%	*M*	*SD*	Range
Gender					
Male	85	63.9			
Female	48	36.1			
Age (years)	131		53.3	13.9	22 – 85
Tumor type					
Astrocytoma I	2	1.5			
Astrocytoma II	5	3.8			
Astrocytoma III	11	8.3			
Glioblastoma multiforme	66	49.6			
Oligodendroglioma	19	14.3			
Other	12	9.0			
Karnofsky Performance Scale	114		82.6	12.6	50-100

Note. *N* = 133. *n* varied due to missing data.

Caregivers were mainly middle age females who were White, married, and the spouse or significant other of the care recipient. Caregivers were well educated, and many were employed outside of the home (47.4%) either full- (*n* = 56) or part-time (*n* = 18). Furthermore, most were overweight or obese (*n* = 74) and reported the presence of least one comorbidity (64.8%) such as high blood pressure, diabetes, cancer, and or stroke. Of the caregivers, 22 reported two comorbidities, six reported three, and two reported four or more comorbidities. A few of the caregivers (35.4%) were providing care not only for the care recipient but for children as well (see Table 3).

Descriptive Statistics

Prior to conducting statistical analyses, data screening was conducted and included screening for errors of data entry, missing data, outliers, distribution of normality, and presence of multicollinearity. Data entry errors and missing data were verified with the primary research team members and corrected based on their responses. For example, the data sent in May 2011 was lacking information on the last 10 caregivers for the MDASI-BT. This was verified as not missing but rather not entered when the dataset was sent. It was updated and resent in June 2011. Those participants whose coefficient variations for the concentration ranges of IL-1ra and IL-6 which were greater than 20% were not used as part of the analysis (*n* = 2, IL-6 CV% were 29.9 and 21 respectively). After consultation with sleep expert (S. Lee, personal communication, August 3, 2011), participants who did not have sleep data for at least 2 nights for averaging (*n* = 1) or who had patterns that indicated a possible sleep apnea (*n* = 2) which could over-estimate WASO were removed from the analysis. The majority of the caregivers had 3 nights of sleep data (*n* = 86), while 20 had 2 nights, and six had 4 nights.

Table 3

Caregiver Characteristics

Characteristic	*n*	%	*M*	*SD*	Range
Gender					
Male	38	28.6			
Female	92	69.2			
Age (years)	130		51.6	11.8	21 – 77
Race					
White	125	94.0			
Black	2	1.5			
American Indian	1	0.1			
Asian	2	1.5			
Relationship to care recipient					
Spouse/significant other	100	75.2			
Parent	10	7.5			
Daughter/son	11	8.3			
Friend/companion	6	4.5			
Other	3	2.3			
Marital status					
Never married	3	2.3			
Currently married/living with significant other	120	90.2			
Widowed	2	1.5			
Separated/divorced	5	3.8			
Year of formal education	127		14.4	2.7	5 - 23
Employment status					
Full-/part-time	74	55.6			
Laid off/unemployed	14	10.5			
Retired: not working	23	17.3			

Characteristic	*n*	%	*M*	*SD*	Range
Employment status					
Full-time homemaker	10	7.5			
Other	9	6.8			
Parental status					
Have Children					
Yes	112	84.2			
No	18	13.5			
Number of children	124		2.4	2.2	0 - 19
Number in home	130		0.6	1.0	0 - 4
Health status					
Number of comorbidities	108		1.1	1.2	0 - 8
Smoking status					
Nonsmoker	96	72.2			
Smoker	19	14.3			
Weight status (BMI)	115		27.6	6.1	16.8 – 47.1
Under weight	5	3.8			
Normal weight	37	27.8			
Over weight	38	28.6			
Obese	36	27.1			

Note. *N* = 133. *n* varied due to missing data.

Major Study Variables

All interval/ratio level variables were assessed by examining skewness, kurtosis, and other assessments for normality of the data as outlined by Field (2009) and Elliott and Woodward (2007). Assessments indicated that all variables were normally distributed except for sleep latency, IL-1ra and IL-6. A log transformation was used for sleep latency and the ILs as suggested by Field (2009). Correction of normality of sleep latency made no difference in parametric and nonparametric relationship testing; therefore, the original variable was used in analysis. However, there were differences for the ILs, and the log transformations were used for data analysis.

Descriptive statistics for variables representing the conceptual sleep loss model including variables associated with sleep deprivation, variables associated with sleep disruption, measures of sleep loss, and measures of adverse health outcomes are displayed in Table 4. Participant characteristics of age, gender, employment, nicotine use, and comorbidities represented in the model were presented in Table 3, and care recipient physical functioning was presented in Table 2. Internal consistency reliability coefficients for all the instruments were adequate and also are presented in Table 4.

On average, the family caregivers reported care recipients having few symptoms, with an average of 6.7 (*SD* = 6.7) out of a total of 21 possible symptoms. The most frequently reported care recipient symptoms were fatigue (60.9%), feeling distressed (52.6%), irritability (50.4%), trouble with remembering (48.9%), difficulty concentrating (44.4%), feelings of sadness (44.4%), disturbed sleep (40.6%), drowsiness (39.1%), weakness (37.65%), and difficulty with understanding (35%). Less than 30% reported the

Table 4

Descriptive Statistics and Cronbach's Alpha Coefficients for Conceptual Variables of Sleep Loss in Caregivers

Variable	*n*	*M* (*SD*)	Observed range	Possible range	α
Sleep deprivation					
MDASI-BT	90	4.0 (2.3)	1-11	1-11	.90
Sleep disruption					
CRA	78	3.9 (0.5)	2.6-5	1-5	.86
POMS	122	8.4 (2.2)	3-15	3-15	.90
Sleep loss					
TST (minutes)	112	356.6 (84.6)	95-544	—	—
WASO	112	15.1 (9.2)	0.5-47.7	—	—
Sleep quality[a]	123	1.3 (0.9)	0-3	0-3	—
Adverse health outcomes					
Physiological dimension					
Interleukin-1ra (pg/mL)	104	366.5 (354.4)	86.7-3349.2	—	—
Interleukin-6 (pg/mL)	105	1.8 (1.3)	0.48-8.3	—	—
MOS SF-36: Physical Health Summary Measure	103	81.2 (17.2)	0-90	0-100	.91

Variable	*n*	*M* (*SD*)	Observed range	Possible range	α
Adverse health outcomes					
Cognitive/behavioral dimension					
MOS SF-36: Vitality Subscale	103	57.1 (20.8)	0-90	0-100	.89
FSQOL	89	63.4 (9.1)	33-80	25-125	.93
Emotional dimension					
CES-D	126	8.3 (6.5)	9-29	0-30	.87
FACIT-Sp	109	35.4 (8.8)	10-48	0-48	.90
Social dimension					
ISEL	123	35.0 (4.9)	17-40	0-40	.89
WLQ	54	10.2 (1.0)	8-13	0-25	.92

Note. MDASI-BT = M.D. Anderson Symptom Inventory-Brain Tumor; CRA = Caregiver Reaction Assessment; POMS = Profile of Mood States; TST = total sleep time; WASO = wake after sleep onset; PSQI = Pittsburgh Sleep Quality Index; MOS SF-36 = Medical Outcomes Study-Short Form 36; FSQOL = Fox Simple Quality of Life; CES-D = Center for Epidemiologic Studies-Depression Scale; FACIT-Sp = Functional Assessment of Chronic Illness Therapy- Spiritual; ISEL = Interpersonal Support Evaluation List; WLQ = Work Limitations Questionnaire.

[a] Item from Pittsburgh Sleep Quality Index

presence of seizures, numbness, dry mouth, difficulty speaking, loss of appetite, change in appearance, visual disturbances, nausea, vomiting, or shortness of breath. Although symptoms were present, caregivers overall were not bothered by the presence of these symptoms (*M* = 4.0, *SD* = 2.33, range 1 to 11). Caregiver reaction (based on the CRA) over the caregiving situation was positive on average. More than half of the caregivers (59.4%) reported experiencing anxiety greater than the midpoint of 8 on the POMS Anxiety-Tension subscale scale (3 to 15). The overall serum levels of IL-1ra ranged from 86.7 to 3349.2 pg/mL (*M* = 366.5, *SD* = 354.41). Interleukin-6 levels ranged from 0.48 to 8.3 pg/mL (*M* = 1.8, *SD* = 1.28). The caregivers' self-reported physical health related QOL as measured by the MOS SF-36 was high (70.9% of the sample scored above 75 on a scale of 1 - 100), and only 7.8% of the sample rated their health as poor (less than 50 on a scale of 1 - 100). On average, caregivers had moderate vitality (60.1% of the sample scored above 50 on a scale of 1 to 100) as measured by the MOS SF-36.

Caregiver QOL was poor, with 85.4% reporting a score less than the midpoint of the FSQOL scale. Furthermore, depressive symptoms were moderate in this sample, with 28.6% of the sample scoring > 10, the commonly used cut off, indicating a possible referral for clinical depression. In the general population, depression is reported to be approximately 9% (Centers for Disease Control and Prevention, 2010). Overall, caregivers reported high spiritual well-being, with the mean falling well above the midpoint of the scale, as well as high perceived social support. For those caregivers who were employed either full- or part-time (*n* = 54), work limitations were low, with average scores below the midpoint of the scale. There was no difference between the caregivers employed full-time (*M* = 10.2, *SD* = 0.8) and those who were employed part-time (*M* =

10.0, $SD = 1.3$), and their work limitations. Physical skills was the lowest rated of the four scales composing the WLQ. Most caregivers wore their accelerometer for 3 nights (76%), while 19% wore them for 2 nights, and 5% wore them for 4 nights.

Research Question

What are the sleep characteristics of family caregivers of those with PMBTs? Sleep latency in caregivers was 35 minutes ($SD = 34.5$, Mdn 24.5), which is twice as long and significantly more than the 15 minutes in the general population, $t(113) = 6.18$, $p < .001$. Average TST was 5 hours and 57 minutes ($SD = 84.6$, Mdn 361.3), significantly less than the general population’s 7 hours, $t(113) = -8.00$, $p < .001$. Caregivers were awake in the night for 15.1% of the TST ($SD= 9.2$, Mdn 13.1), significantly higher than the general population’s 10%, $t(111) = 5.84$, $p < .001$. Male caregivers in the study had an average of 328 minutes ($SD = 85.6$) of TST, whereas female caregivers had an average of 368 minutes ($SD = 82.1$; $t(31) = 2.61$, $p = .014$)—both of which were lower than the general population’s 420 minutes.

On average, caregivers awakened at 7:09 a.m. ($SD = 120.8$ minutes, range 3:36 a.m. 10:35 a.m.), aroused an average of 8.3 times ($SD = 3.5$, range 2 -21) in the night as reflected on the accelerometers, and adhered to an average bedtime of 11:04 p.m. ($SD = 111.4$ minutes, range 8:44 p.m. to 2:22 a.m.). The caregivers napped an average of 0.4 times ($SD = 0.7$, range 0 to 5), for an average of 16.4 minutes ($SD = 23.5$, range 0 to 121). Self-reported sleep quality was on average fairly good to good ($n = 81$); however, 31.6% of the caregivers reported fairly bad or very bad sleep quality.

To determine the synchronicity of the sleep/wake cycle in the caregivers, bivariate correlations were calculated between the bedtimes and arousal times. The sleep/wake cycle of this sample was asynchronous. Bedtimes were moderately correlated from sleep period to sleep period among the caregivers (r ‘s = .41 to .46, $p < .001$). However, arousal times showed a variety of relationships: (a) a strong relationship between sleep arousal Day 1 and Day 2 ($r = .57$, $p < .001$), (b) a moderate relationship between Day 2 and Day 3 ($r = .43$, $p < .001$), and (c) a small relationship between Day 1 and Day 3 ($r_s = .29$, $p = .005$), indicating an asynchronous pattern among the lay down and arousal times. For a pattern that is synchronous, one would expect very strong correlations consistently from one sleep period to another at .80 or higher. Sleep times were only calculated on those caregivers who wore their accelerometers for 2 or 3 nights. There were only six participants who wore the accelerometers for 4 nights.

Caregiver self-perceptions of sleep latency differed significantly from that of the accelerometer data. Caregivers reported an average of 24.9 minutes (*SD* = 26.8; range 0 to 180) to fall asleep whereas the accelerometer data indicated an average of 35.4 minutes (SD = 35.3, range 0 to 209; $t = 3.10$, $p = .002$). Caregivers also perceived less WASO time (10.5%) than what was recorded by the accelerometer (15.1%; $t = 5.26$, $p < .001$).

Relationships among Descriptive Characteristics and Major Study Variables

Bivariate correlations were used to examine relationships among caregiver characteristics, the predictor variables and health outcomes. Pearson’s correlation coefficients (r) were calculated for those variables which were normally distributed, while Spearman’s rho correlation coefficient (r_s) was calculated for the relationships involving sleep latency. Among the sample characteristics, older age was associated with lower educational status ($r = -.29$, $p = .001$), not being employment ($r = .23$, $p = .007$), and being a nonsmoker ($r = .21$, $p = .022$). Longer TST was significantly associated with poorer self-reported sleep quality (*r* = .21, *p* = .031), less WASO (*r* = .54, *p* < .001), and increased sleep efficiency (*r* = .54, *p* = < .001). Increased sleep latency was associated with poorer sleep quality (*r* = .23, *p* = .016). There was not a relationship between WASO and self-reported sleep quality (*r* = -.18, *p* = .074), nor were there any significant relationships between sleep latency and TST (*r* = -.08, *p* = .419) or WASO (*r* = -.17, *p* = .071). These relationships are reported in Tables 5, 6, and 7.

There were significant relationships among the sleep deprivation and sleep disruption predictors of sleep loss (see Table 5). Relationships included (a) longer TST in females, in caregivers of care recipients with higher physical functioning, and those with higher anxiety; (b) less WASO associated with being employed, care recipients with high physical functioning, and higher anxiety; and (c) higher anxiety associated with poorer sleep quality. Longer sleep latencies were associated with more caregiver bother of care recipient symptoms.

There were several significant relationships among all of the predictor variables (sleep deprivation, sleep disruption, and sleep loss) and the health outcomes (see Table 6). The significant relationships in the physiological health dimension of the health outcomes included higher levels of IL-1ra with older caregivers and more comorbidities. Higher levels of IL-6 were associated with older age. Poorer physical health was associated with increased number of comorbidities while better physical health was associated with higher care recipient functioning.

In the cognitive/behavioral dimension, higher vitality (meaning lower fatigue) was associated with those who smoked, whereas higher fatigue was associated with higher anxiety and longer TST. Better QOL was associated with more WASO, while

Table 5

Relationships Among Caregiver Characteristics and Sleep Predictors Variables

Variable	TST	WASO	Sleep quality[a]	Sleep latency[b]	Sleep efficiency
Age[b]	-.07	-.02	-.03	-.11	.02
Gender[b]	.21*	-.00	-.10	-.06	.00
Race[b]	-.15	.11	-.11	.09	-.11
Years of education	.06	.05	.07	.02	-.05
Relationship to CR	.00	-.16	-.08	-.06	.16
Employment status	.10	-.19*	.03	.11	.19*
Smoking status	-.12	.02	.13	.15	-.02
Number of comorbidities	-.09	-.04	-.01	-.14	.04
Body mass index	-.12	.07	-.05	-.02	-.07
CR tumor type	-.02	.03	-.09	-.09	-.03
CR Karnofsky score	.22*	-.21*	-.04	.06	.21*
Bother score on MDASI	-.03	-.01	-.04	.23*	.01
POMS-Anxiety	.25**	-.24*	.39**	.16	.24*
CRA	-.01	-.10	-.09	-.20	.10

Note. TST = total sleep time; WASO = wake after sleep onset; CR = care recipient; MDASI= M.D. Anderson Symptom Inventory; POMS = Profile of Mood States; CRA = Caregiver Reaction Assessment.
[a]Sleep quality item from Pittsburgh Sleep Quality Index. [b]Spearman’s rho reported.
*p < .05, **p < .01.

Table 6

Relationships Among Model Predictor Variables and Caregiver Health Outcome Variables

Variable	Il-1ra	IL-6	PHealth	Vitality	FSQOL	CES-D	FACIT-Sp	ISEL	WLQ
Sleep deprivation variables									
Age	.27**	.21*	.11	-.07	-.09	-.01	-.12	-.06	.21
Gender	.17	.19	-.07	-.03	-.15	-.05	.01	.02	.04
CR Karnofsky score	.04	.06	.23*	.15	.01	-.02	.15	.04	.01
Bother score on MDASI	.14	.13	-.10	.05	-.14	-.03	-.02	.06	-.03
Employment status	-.15	-.06	-.02	-.02	-.07	.07	.00	-.01	-.05
Sleep deprivation variables									
POMS-Anxiety	.20	.03	.08	-.22*	-.39**	.30**	-.20*	-.17	.01
CRA	-.03	-.19	.11	.21	.15	.01	.07	.24*	-.15
Smoking status	-.14	-.04	.02	.21*	-.05	.24*	-.11	.00	-.12
Number of comorbidities	.25*	.14	-.44**	-.12	-.04	-.05	.00	-.12	.21
Sleep loss variables									
TST	.18	-.10	-.06	-.25*	-.33**	-.01	-.05	-.25**	.13
WASO	-.11	.15	.03	.02	.33**	-.06	.09	.19	-.18
Sleep quality[a]	-.05	.01	.05	-.15	-.39**	.17	-.21*	-.22*	-.04

Note. IL = Interleukin; Phealth= Medical Outcomes Study-Short Form 36 subscale: Physical Health; FSQOL = Fox Simple Quality of Life; CES-D = Center for Epidemiologic Studies-Depression Scale; FACIT-Sp = Functional Assessment of Chronic Illness Therapy- Spiritual; ISEL = Interpersonal Support Evaluation List; WLQ = Work Limitations Questionnaire; CR= Care Recipient; MDASI= M.D. Anderson Symptom Inventory; POMS = Profile of Mood States; CRA = Caregiver Reaction Assessment; TST = total sleep time; WASO = wake after sleep onset.
[a] Sleep quality item from Pittsburgh Sleep Quality Index.
*p < .05, **p < .01

worse QOL was associated with increased anxiety, longer TST, and poorer sleep quality. Within the emotional dimension of the health outcomes, higher depressive symptoms were associated with higher caregiver anxiety and those caregivers who smoked. Those caregivers who experienced a strong sense of spirituality reported less anxiety and better sleep quality. In the social dimension, those caregivers who perceived greater social support had a more positive reaction to caregiving. Those who perceived less social support reported poorer sleep quality and had longer TST. There were no significant relationships with work limitations.

Among the health outcome variables, caregivers who had less fatigue had better QOL and social support and fewer depressive symptoms (see Table 7). Those caregivers who had higher depressive symptoms reported a lower sense of spirituality. For caregivers, better QOL was associated with higher spirituality and social support. Those with higher spirituality also had higher social support. For those caregivers who were employed either full- or part-time (*n* = 54), fewer work limitations were associated with fewer depressive symptoms. However, those with more work limitations had higher IL-1ra levels.

Further exploration of the data through either median split or cut off scores from the literature revealed that those caregivers with higher anxiety differed from those caregivers with lower anxiety. Those with higher anxiety had more depressive symptoms (M = 9.4, SD = 6.50; M = 7.7, SD = 6.76 respectively; $t(82) = 2.93$, p =.004). Interleukin levels of IL-1ra and IL-6 were higher those caregivers who were overweight or obese (BMI's > 25; $t(72) = 4.08$, $p < .001$ and $t(73) = 3.12$, $p = .003$, respectively). Caregivers who self-reported poorer quality of sleep had higher IL-1ra levels, $t(70) = 2.02$, $p = .047$,

Table 7

Relationships Among Caregiver Health Outcomes

Variable	Il-1ra	IL-6	PHealth	Vitality	FSQOL	CES-D	FACIT-Sp	ISEL
Il-1ra								
IL-6	.47**							
PHealth	.00	-.06						
Vitality	-.02	-.19	.32**					
FSQOL	.05	.13	.12	.26*				
CES-D	-.05	.04	.15	-.26**	-.11			
FACIT-Sp	.10	-.08	-.09	.19	.44**	-.34**		
ISEL	.01	.06	.06	.37**	.52**	-.15	.53**	
WLQ	.34*	-.08	-.28	.04	-.22	-.35**	.00	-.15

Note. IL = Interleukin; Phealth= Medical Outcomes Study-Short Form 36 subscale: Physical Health; FSQOL = Fox Simple Quality of Life; CES-D = Center for Epidemiologic Studies-Depression Scale; FACIT-Sp = Functional Assessment of Chronic Illness Therapy-Spiritual; ISEL = Interpersonal Support Evaluation List; WLQ = Work Limitations Questionnaire.
**p* < .05, ***p* < .01.

than those with better quality of sleep; however, there were no differences between sleep quality in caregivers and IL-6 levels, t(70) = -.16, p = .875. Those caregivers with higher depressive symptoms and higher anxiety had no differences in their IL-1ra and IL-6 levels from caregivers with fewer depressive symptoms and less anxiety.

Hypothesis Testing

Hierarchical regression models were used to examine contributions of sleep deprivation, sleep disruption, and sleep loss with health outcomes. Appendix D shows the full regression models as hypothesized. Further model testing included use of the bivariate correlations of all independent variables which were examined with the outcome variables. To create more parsimonious models, if a variable was correlated with the outcome variable at the .19 level or higher, it was included the regression models. Age and gender were not significantly associated with the study variables as previously theorized except for gender with TST and age with work limitations; therefore, age and gender were not used as covariates in the regression models.

Hypothesis 1

Sleep deprivation (caregiving demands, a reflection of care recipient function; care recipient physical function; and employment) and sleep disruption (stress, anxiety, nicotine use, and health conditions) will contribute significant variance to sleep loss (TST, WASO, and sleep quality) while controlling for age and gender.

Three separate hierarchal regression models were conducted to address this hypothesis pertaining to variables associated with the three variables representing sleep loss. These three models are in Table 8.

Table 8

Variables Associated with Caregiver Sleep Loss

	Sleep loss variable											
	TST				WASO				Sleep quality[a]			
Predictor	B	SE B	β	ΔR^2	B	SE B	β	ΔR^2	B	SE B	β	ΔR^2
Step												
Gender	9.9	18.4	.06	.02								
Step (deprivation)												
Karnofsky score	1.3	.66	.28*	.04	-.15	.07	-.20*					
Employment status					-.4.8	1.9	-.26*	.04*				
Step (disruption)												
POMS-Anxiety	9.1	3.1	.28**	.08**	-.87	.37	-.24*	.10**	.12	.03	.39**	.15**
Total R^2				.14**				.15**				.15**
Overall model	$F(3,89) = 4.73$, $p = .004$				$F(3,87) = 4.92$, $p = .003$				$F(1,117) = 20.86$, $p \leq .001$			
n		92				90				118		

Note. TST = total sleep time; WASO = wake after sleep onset; POMS = Profile of Mood States.
[a] Sleep quality item from Pittsburgh Sleep Quality Index.
* $p < .05$. ** $p < .01$.

For the first model, gender, care recipient physical functioning, and anxiety (POMS) were associated with the dependent sleep loss variable of TST and included in the model. The overall TST model was significant, with higher care recipient physical functioning (t = 2.0, p = .045) and higher anxiety (t = 2.9, p = .005) as significant predictors of longer TST. These predictors accounted for 14% of the variance in the TST model.

In the second model, the independent variables of care recipient physical functioning, anxiety, and employment were included in the model for WASO. The overall WASO model was significant. Those caring for care recipients with higher physical functioning (t = -2.1, p = .043), being unemployed (t = -2.5, p = .013), and having lower anxiety (t = -2.4, p = .020) were significant predictors of more awakenings in the night. These predictors accounted for 15% of the variance in the WASO model.

For the third model, anxiety was the only variable included in the model with sleep quality as the dependent variable. Anxiety (t = 4.6, p = < .001) was a significant predictor of sleep quality with higher anxiety associated with poorer sleep quality. The overall model for sleep quality was significant with higher anxiety accounting for 15% of the variance within the model.

All three models were statistically significant with the variance in sleep loss variables explaining a range of 14% - 15%. The hypothesis was only partially supported as many of the hypothesized variables—such as caregiving demands, care recipient functioning, caregiver stress, nicotine use, and caregiver comorbidities—were not associated with sleep loss.

Hypothesis 2

Sleep deprivation (caregiving demands, a reflection of care recipient function; care recipient physical function;, and employment), sleep disruption (stress, anxiety, nicotine use, and health conditions), and sleep loss (TST, WASO, and sleep quality) will contribute significant variance to adverse physiological health outcomes (altered immune function [increased serum levels of Interleukin 1 and Interleukin 6] and poorer physical health) while controlling for caregiver age and gender.

Three separate hierarchal regression models were conducted to address this hypothesis pertaining to variables associated with physiological health outcomes. These three models are in Table 9.

For the first model, age and care recipient physical functioning (Karnofsky score) were associated with the dependent physiological health dimension variable IL-1ra and included in the model. Older caregiver age and higher care recipient functioning were associated with increased levels of IL-1ra. Older age ($t = 3.0$, $p = .005$) was a significant predictor of higher IL-1ra levels. The two variables accounted for 9% of the variance in the IL-1ra model.

In the second model, the independent variable of caregiver age was included in the model for dependent physiological health dimension variable IL-6. The overall IL-6 model was significant with older age associated with higher IL-6 levels. Age ($t = 2.2$, $p = .030$) was a significant predictor of IL-6 levels and accounted for 5% of the variance in the IL-6 model.

For the third model, the care recipient physical functioning and number of comorbidities were included in the model. The number of comorbidities ($t = -4.8$, $p <$

Table 9

Variables Associated with Caregiver Physiological Health

	Health outcome: Physiological											
	Interleukin 1ra				Interleukin 6				Physical health			
Predictor	B	SE B	β	ΔR^2	B	SE B	β	ΔR^2	B	SE B	β	ΔR^2
Step												
Age	.01	.00	.30**	.08*	.01	.01	.21*	.05*		—		
Step (deprivation)												
Karnofsky score	.00	.00	.10	.01		—			.25	.14	.18	.06*
Step (disruption)												
Comorbidities		—				—			-.69	1.4	-.46**	.20**
Total R^2				.09*				.05*				.26**
Overall model	$F(2, 85) = 4.26, p = .017$				$F(1, 102) = 4.86, p = .03$				$F(2, 84) = 14.94, p \leq .001$			
n		87				103				86		

* $p < .05$. ** $p < .01$.

.001) was an independent predictor of physical health with those caregivers with more comorbidities being associated with poorer physical health. The overall model for physical health was significant with comorbidities accounting for 26% of the variance in the model.

All three models were statistically significant with the variance explained at 9% for the IL-1ra and 5% for the IL-6 models, and 26% of the variance explained in physical health. The hypothesis was only partially supported as many of the variables hypothesized to affect physiological health—such as care recipient functioning, caregiver stress, anxiety, nicotine use, TST, and sleep quality—were not associated with altered physiological health.

Hypothesis 3

Sleep deprivation (caregiving demands, a reflection of care recipient function; care recipient physical function; and employment), sleep disruption (stress, anxiety, nicotine use, and health conditions), and sleep loss (TST, WASO, and sleep quality) will contribute significant variance to adverse cognitive/behavioral outcomes (higher fatigue and poorer overall QOL) while controlling for caregiver age and gender.

Two separate hierarchal regression models were conducted to address this hypothesis pertaining to variables associated with cognitive/behavioral health outcomes. The two models are in Table 10.

For the first model, anxiety, caregiver stress (CRA), nicotine use, and TST were associated with the dependent cognitive/behavioral health dimension variable vitality (fatigue) and included in the model. The overall vitality model was not statistically significant.

Table 10

Variables Associated with Caregiver Cognitive/Behavioral Health

Predictor	Health outcome: Cognitive/behavioral							
	Vitality				Quality of life			
	B	SE B	β	ΔR^2	B	SE B	β	ΔR^2
Step (disruption)								
POMS-Anxiety	-.72	1.08	-.09		-.66	.43	-.19	.15**
CRA	5.83	5.34	.14			—		
Smoking status	9.08	7.73	.16	.09		—		
Step (sleep loss)								
TST	-.06	.04	-.23	.04	-.01	.02	-.07	
WASO		—			.19	.13	.20	
Sleep quality[a]		—			-3.2	1.3	-.28*	.13*
Total R^2				.14				.27**
Overall model	*F*(4, 53) = 2.08, *p* = .097				*F*(4, 66) = 6.19, *p* = .001			
n	57				70			

Note. POMS = Profile of Mood States; CRA = caregiver reaction assessment; TST = total sleep time; WASO = wake after sleep onset.
[a] Item from Pittsburgh Sleep Quality Index.
* *p* < .05. ***p* < .01.

In the second model, the independent variables of anxiety, TST, WASO, and sleep quality were included in the model for dependent cognitive/behavioral health dimension variable QOL. The overall QOL model was significant. Sleep quality (t = -2.3, p = .022) was a significant predictor of QOL, whereas anxiety, TST, and WASO were not. The overall QOL model was significant with those caregivers with better sleep quality experiencing better QOL. All variables in the model accounted for 27% of the variance in the QOL model.

Only one of the two models was statistically significant with 27% of the variance explained in overall QOL. The hypothesis was only partially supported as some of the variables hypothesized to affect cognitive/behavioral health outcomes—such as caregiver demands, care recipient functioning, and employment status—were not associated with cognitive/behavioral health outcomes.

Hypothesis 4

Sleep deprivation (caregiving demands, a reflection of care recipient function; care recipient physical function, and employment), sleep disruption (stress, anxiety, nicotine use, and health conditions), and sleep loss (TST, WASO, and sleep quality) will contribute significant variance to adverse emotional outcomes (higher depression and lower spiritual well-being) while controlling for caregiver age and gender.

Two separate hierarchal regression models were conducted to address this hypothesis pertaining to variables associated with emotional health outcomes. The two models are in Table 11.

For the first model, anxiety and nicotine use were associated with the dependent emotional health dimension variable depressive symptoms and included in the model.

Table 11

Variables Associated with Caregiver Emotional Health

	Health outcome: Emotional							
	Depression				Spiritual health			
Predictor	B	SE B	β	ΔR^2	B	SE B	β	ΔR^2
Step (disruption)								
POMS-Anxiety	.49	.25	.19**		-.43	.36	-.13	.04*
Smoking status	3.6	1.8	.18*	.14**		—		
Step (sleep loss)								
Sleep quality[a]		—			-1.8	1.2	-.16	.02*
Total R^2				.14**				.06*
Overall model	$F(2, 101) = 8.28, p = .001$				$F(2, 100) = 3.20, p = .045$			
n		103				102		

Note. POMS = Profile of Mood States.
[a] Item from Pittsburgh Sleep Quality Index.
* $p < .05$. ** $p < .01$.

The overall depressive symptoms model was significant. Higher anxiety (*t* = 3.0, *p* = .004) and nicotine use (*t* = 2.6, *p* = .012) were significant predictors of depressive symptoms. Caregivers who smoked and had higher levels of anxiety had higher levels of depressive symptoms. All variables in the model accounted for 14% of the variance in the depressive symptoms model.

In the second model, the independent variables of anxiety and sleep quality were included in the model for the dependent emotional health dimension variable spiritual wellness. The overall spiritual wellness model was significant although there were no significant predictors of spiritual wellness. These variables accounted for 6% of the variance in the model.

Both models were statistically significant with the variance explained in emotional health ranging from 6% - 17%. The hypothesis was only partially supported as many of the variables hypothesized to affect emotional health outcomes—such as caregiving demands, employment status, caregiver stress, caregiver comorbidities, TST, and WASO—were not associated with emotional health outcomes.

Hypothesis 5

Sleep deprivation (caregiving demands, a reflection of care recipient function; care recipient physical function; and employment), sleep disruption (stress, anxiety, nicotine use, and health conditions), and sleep loss (TST, WASO, and sleep quality) will contribute significant variance to adverse social outcomes (poorer social interactions and poorer work interactions for those caregivers who are employed) while controlling for caregiver age and gender.

Two separate hierarchal regression models were conducted to address this hypothesis pertaining to variables associated with social health outcomes. The two models are in Table 12.

For the first model, caregiver stress, TST, WASO, and sleep quality were associated with the dependent social health dimension variable social support and included in the model. The overall social support model was not statistically significant.

In the second model, the independent variables of age and number of comorbidities were included in the model for dependent social health dimension variable work limitations. The overall work limitations model was significant. The number of comorbidities (t = 3.4, p = .002) was a significant predictor of work limitations with those caregivers with more comorbidities experiencing higher work limitations. Comorbidities and age accounted for 26.1% of the variance in the work limitations model.

Only one of the two models was statistically significant with 26% of the variance in work limitations explained. The hypothesis was only partially supported as some of the variables hypothesized to affect social health outcomes—such as caregiver demands, care recipient functioning, employment status, anxiety, and nicotine use—were not associated with social health outcomes.

This chapter presented the results of a descriptive, correlational study using a secondary data analysis to determine sleep loss and its health effects among caregivers of those with PMBTs. A description of care recipient and caregiver characteristics as well as caregiver sleep characteristics were reported. Findings from accelerometers worn during caregiver sleep and self-report instruments and hypothesis testing were also presented.

Table 12

Variables Associated with Caregiver Social Health

	Health outcome: Social							
	Social support				Work limitations			
Predictor	B	SE B	β	ΔR^2	B	SE B	β	ΔR^2
Step								
Age		—			.02	.01	.27*	.06
Step (distruption)								
CRA	1.8	1.2	.20			—		
Comorbidities		—			.34	.10	.44**	.20**
Step (sleep loss)								
TST	-.01	.01	-.15			—		
WASO	.06	.08	.13			—		
Sleep quality[a]	-.27	.81	-.04	.07		—		
Total R^2				.10				.26**
Overall model	$F(4, 56) = 1.60, p = .187$				$F(2, 43) = 7.58, p = .002$			
n		60				45		

Note. CRA = caregiver reaction assessment; TST = total sleep time; WASO = wake after sleep onset.
[a]Item from Pittsburgh Sleep Quality Index.
* $p < .05$. ** $p < .01$.

CHAPTER V

DISCUSSION AND CONCLUSION

A discussion of the study findings and conclusion are presented. The implications of findings for nursing practice and the strengths and limitations of the study are identified. Recommendations for future research are presented for consideration.

Sleep impairments and their effects on physical and mental health are well documented (Banks & Dinges, 2011; Bonnett, 2011; Von Dongen et al., 2003a, Von Dongen et al., 2003b). Informal family caregivers report sleep impairments, as well as high levels of anxiety, and depression (Beaudreau et al., 2008; Carter, 2005; Carter 2006; Castro et al., 2009; Rowe et al., 2008; Rowe, Kairalla, & McCrae, 2010); however, because of the paucity of literature on caregivers of those with a PMBT, it is unknown what sleep impairments, if any, that this specific caregiving population experiences. This study adds to the limited body of knowledge of sleep and the health of caregivers of those with PMBTs at time of tumor diagnosis.

Sleep Characteristics of Caregivers of Persons with PMBTs

Caregivers in this study experienced sleep impairments similar to other caregiving populations (e.g., dementia and cancer) that have been intuitively compared to caregivers of those with PMBTs. The average nocturnal sleep in the caregivers in this study was about 6 hours, similar to a small sample of female caregivers (*n* = 9) of those with dementia whose sleep was measured with home PSG (TST = 341.9 minutes; Castro et al., 2009). However, the TST for caregivers of persons with PMBTs was longer than the TST of 60 female caregivers of those with dementia (TST = 323 minutes; Beaudreau et al., 2008) and nine bereaved caregivers of those with cancer who self-reported a TST of 260 minutes (Carter, 2005) and 15 bereaved caregivers of those with cancer who were controls in a sleep intervention study (TST = 330 minutes; Carter, 2006). Conversely, TST was shorter than reported for (a) 31 older caregivers of those with dementia (TST = 395.2 minutes; as measured by actigraphy; Rowe et al., 2008), (b) 27 control caregivers of those with dementia (TST = 390.7 minutes; as measured by actigraphy; Rowe et al., 2010), and (c) 20 caregivers of those with dementia (TST 409.5 minutes; as measured by home PSG; Fonareva et al., 2011). Although it is a challenge to compare nocturnal sleep times across the caregiving populations because of different methodological approaches to sleep measurement, all report TSTs that are less than the recommended 7 hours (420 minutes) necessary for the restorative functions of sleep (AASM, 2010; Bonnet, 2011; Carter, 2005). Factors related to sleep times in the selected caregiver studies included (a) age (Beaudreau et al., 2008; Castro et al., 2009; Rowe et al., 2008), (b) presence of depressive symptoms (Beaudreau et al., 2008; Castro et al., 2009; Rowe et al., 2008), (c) worry (Rowe et al., 2010), (d) poor self-rated health (Beaudreau et al., 2008), (e) care recipient sleep patterns (Castro et al., 2009), (f) night to night variability in TST (Rowe et al., 2008), and (g) lack of a sleep routine or poor sleep hygiene (Carter, 2005; Carter, 2006). In this study, anxiety, gender and physical functioning of the care recipient were related to TST.

Sleep latency, the time it takes one to fall asleep after laying down, was approximately 35 minutes for caregivers of persons with PMBTs. This differs significantly from other actigraphical reports with sleep latency times ranging from 11.1 to 25.3 minutes (Beaudreau et al., 2008; Carter, 2006; Rowe et al., 2008; Rowe et al., 2010). Castro et al. (2009) found a shorter sleep latency of 19.8 minutes using home PSG, while Fonareva et al. (2011) reported a sleep latency of 17.3 minutes using home PSG. Carter (2005) found similar self-reported sleep latency (37 minutes) like the accelerometer findings of this study. With the exception of the Carter (2006) study, all of these caregiving studies have sleep latencies that are beyond the normal 15 minutes as defined by AASM (2010). For those caregivers who must arise at predetermined times, this leads to shortened TSTs. For those who are not able to fall asleep in what is perceived a timely manner, there is a higher risk for anxiety over sleep latency to contribute to other sleep disruptions and poor sleep hygiene practices (Lee, 2003; Stepanski et al., 1984; Stepanski & Wyatt, 2003).

WASO was an average of 15.1% of the TST in caregivers of persons with PMBTs. This is significantly different than the 10% in the general population ($p < .05$). The percentage of WASO was also significantly shorter than from the 19.7% and 34.7% ($p < .05$) in caregivers in Castro et al.’s (2009) and Beaudreau et al.’s (2008) research, respectively. WASO was similar to actigraphical findings in cancer caregivers (13.6%, n.s.; Carter, 2006). However, there was significantly less WASO time ($p < .05$) in caregivers with sleep measured using home PSG (13.1%; Fonareva et al., 2011) and actigraphy (12.3%; Rowe et al., 2008 and 13%; Rowe et al., 2010). See Appendix E for further statistical information of the comparison of the sleep measures of TST, sleep latency, and WASO.

The caregivers of persons with PMBTs had approximately double (8.3 times) the number of arousals in the night compared to caregivers in Castro et al.'s (2009) study (4.1 times) and Rowe et al.'s (2010) study (4.7 times). However, Beaudreau et al. (2008) found more arousals in their caregivers of those with dementia (17.2 times) as measured by actigraphy as did Fonareva et al. (2011) using home PSG (51.3 times). The duration of the arousals was not measured. Arousals in the night, especially of long durations, may shorten the TST and the restorative ability of sleep on cognition, motor performance, and learning (Banks & Dinges, 2011; Hamilton et al., 2007; Kunz & Hermann, 2000). The more frequent the arousals in the night, the more fragmented the sleep which has been shown to be worse than shortened sleep times that are not interrupted. Studies have shown that those with very brief periodic arousals from sleep have the same impairments as seen in those with total sleep deprivation (Bonnet, 2011).

Although there are significant differences in TST, sleep latency, WASO, and number of arousals in nocturnal sleep of the various caregiver sleep studies, all illuminate sleep impairments such as shortened sleep times and fragmentation of sleep seen almost universally in caregivers. Although methodologies may differ, each population differs from the norms associated with normal restorative sleep. These differences illuminate the difficulty in comparing caregivers of different populations who may experience different types of caregiving functions and stressors. The differences also highlight the problem in assuming that all caregivers experience similar sleep impairments and should be treated the same. Difficulty going to sleep, staying asleep, being interrupted in sleep, and not receiving enough sleep impact the sleep architecture in different manners and need to be approached differently when intervening (McCurry et al., 2007). This need for different approaches underscores the importance of examining sleep loss in each unique caregiving population and assessing the antecedents to the impairments and needs for intervention. For PBMT caregivers, the sleep situation prior to diagnosis of the brain tumor as well as variables that are impacting sleep after diagnosis need to be examined specifically instead of assuming that sleep impairments in this population are similar to sleep impairments in other caregiving populations. Furthermore, there is a need for more standardization in the measurement of sleep and other related variables for comparison across research. For example, use of subjective and objective measures of sleep such as the PSQI and actigraphy would enable triangulation of information within studies as well as among studies.

Perceptions of sleep impairments by the caregivers of persons with PMBTs were significantly different from the objective data. When questioned about how long it took to fall asleep, on average the caregivers reported less time than the data collected from accelerometers. Caregivers of persons with PMBTs also perceived less WASO than found with the accelerometers ($p < .05$). The underreporting of some aspects of sleep is consistent with findings that those with chronic sleep restrictions underestimate the degree of neurobehavioral dysfunction induced by sleep loss (Banks & Dinges, 2011).

The fragmentation of sleep and shorter sleep times have negative impacts on caregivers' health. In noncaregiving populations, fragmented sleep has been shown to interfere with cognition including task attention, acquisition of new knowledge, and short term memory (Banks & Dinges, 2011; Bonnet, 2011; Cole & Richards, 2005). If sleep disruptions continue, caregivers of persons with PMBTs may be at risk for depression, cardiovascular disease, and even mortality. There is strong evidence that sleep that is chronically restricted to less than 7 hours a night, such as that which results from caregiving, leads to cognitive impairments that become progressively worse. Those who routinely receive only 4 to 6 hours of sleep may experience the same cognitive impairments of individuals who have been awake for 24 to 48 hours (Banks & Dinges, 2011; Van Dongen, Maislin et al., 2003). For those who must provide care, cognitive impairments from either deprived sleep or fragmented sleep may interfere with the ability to (a) make decisions for cognitively impaired care recipients or (b) remain in the caregiving role.

Sleep Variable Predictors of Health Outcomes

Several independent predictors of sleep loss (gender, anxiety, care recipient physical functioning, and employment status) and health outcomes (age, caregiver response to care recipient symptoms, presence of comorbidities, WASO, sleep quality, smoking status, and physical functioning of the care recipient) were identified. Hypothesis testing elicited only partial support of the hypotheses, with sleep deprivation and sleep disruption contributing little variance in either sleep loss or the health outcomes. Although there was sleep loss in caregivers of persons with PMBTs when compared to the general population, sleep loss may have not been present long enough to affect the caregiver’s health. Baseline data were collected 8 to 12 weeks after diagnosis. Given a longer time in the caregiver role, the sleep debt may become larger if sleep loss persists, resulting in more pronounced effects on caregiver health. Studies of sleep and caregiver health across the trajectory of care are needed.

Predictors of Sleep Loss

Although anxiety was consistently an independent predictor of sleep loss, few other sleep deprivation and sleep disruption variables were associated with the sleep loss variables of TST, WASO, and sleep quality as hypothesized. Longer sleep times were associated with female gender, higher care recipient physical functioning, and higher anxiety. The longer sleep times in the female caregivers is an expected finding; in general, both on actigraphical and PSG measures, adult healthy females sleep longer (Baker, O'Brien, & Armitage, 2011). The caregivers in this study were predominately female similar to most caregiving literarure. However, the average TST of this caregiving population was less than the recommended 7 hours, which has implications for caregiver health (as previously discussed)—especially for those caregivers who are male. An explanation for the longer TSTs and less WASO associated with higher care recipient functioning may be that the PBMT caregiver does not have to be as vigilant or provide care during the night for the care recipient when compared to those PMBT caregivers whose care recipient has poorer physical functioning as result of the PMBT.

The finding of higher anxiety being associated with longer TSTs is different than what is reported by the literature on anxiety disorders, which typically includes longer sleep latencies, difficulty maintaining sleep in the night, and shorter sleep durations (Monti & Monti, 2000; Papadimitriou & Linkowski, 2005; Ramsawh, Stein, & Mellman, 2011). In the caregiving literature, comparisons between caregivers and noncaregivers showed either no difference in sleep time when controlling for age (Castro et al., 2009) or shorter sleep times in the caregivers as compared to noncaregivers (Fonareva et al., 2011; Rowe et al., 2008; Rowe et al., 2010). The findings in the current study suggest that like those with anxiety disorders, caregivers experience longer sleep latencies; however, other factors besides anxiety awaken caregivers in the night. Those caregivers who were not experiencing high anxiety had shorter sleep durations, which may have been impacted by other circumstances, such as nocturnal wanderings by the care recipient (Brummett et al., 2006) or the presence of caregiver comorbidities (Berger et al., 2005). Those caregivers with high levels of anxiety had less WASO than those with low levels of anxiety, which would result in longer TSTs.

Current professional literature suggests that there is a bidirectional effect of sleep loss on symptoms of anxiety, i.e., sleep deprivation leads to an increase in state symptoms of anxiety in individuals who do not meet the criteria for an anxiety disorder (Babson, Trainor, Feldner, & Blumenthal, 2010). Like the reports of other caregivers with anxiety (Berger et al., 2005; McCurry et al., 2007), this caregiving population reported poorer sleep quality when experiencing higher levels of anxiety. Anxiety was the only predictor of poor sleep quality, and yet, the caregivers of persons with PMBTs who had higher anxiety also had longer TSTs and less WASO, which is usually associated with better perceptions of sleep quality. These perceptions of sleep quality may have been confounded by the higher depressive symptoms in those with anxiety as well as the overall poorer perception of QOL in the caregivers in this study. Studies have shown that those with depressive symptoms report poorer sleep satisfaction while those with anxiety report poorer sleep latency (Babson et al., 2010; Mayers et al., 2009).

Besides higher anxiety, being employed was also associated with less WASO. Although the effects of employment on sleep have not been reported in the caregiving literature, it is reasonable to think that those who are employed may experience more fatigue and a higher sleep propensity. In this study, although not significantly correlated, those who were employed had less vitality or experienced more fatigue. Therefore, they may sleep more efficiently at night to restore the homeostatic balance between sleep need and arousal, which may help to explain why employed caregivers had less WASO. Furthermore, depending on the type of employment and hour of arrival at work, there may be shifts in the sleep/wake circadian cycle. For those who work night shifts or early morning shifts (arriving to work between 4 a.m. and 7 a.m.), there is a high incidence of sleepiness in this population and shifts in the endogenous sleep/wake cycle (Drake & Wright, 2011). Sleep debt accumulates and increases the sleep propensity as previously discussed. Although employment status was known in this study, what hours of employment were not.

The other sleep deprivation and disruption variables, such as age, caregiving demands, caregiver stress, the presence of comorbidities or nicotine use did not significantly contribute to the variance seen in sleep loss in the current study. Presence of comorbidities or nicotine use may not have been significant in this study as the sample was fairly homogenous, whereas age was distributed across the years. It is known that age effects sleep architecture at different times in the lifespan, and with the wide distribution of age, these effects were not apparent. The shortened caregiving time may help to explain why caregiver stress related to providing care or caregiver reactions to care recipient symptoms were not predictive early in the illness trajectory. The predictors only explained a minimal amount of variance in the models, indicating that there are other factors associated with sleep loss—such as poor sleep hygiene, sleeping with the care recipient who may have disordered sleep or snore, presence of caregiver sleep disorder such as restless leg movements, or something as simple as consuming large meals or caffeine before sleep.

Predictors of physiological health. Il-1ra and IL-6 are inflammatory cytokines that have been implicated in sleep problems such as daytime sleepiness, insomnia, and delayed sleep onset (Kapsimalis et al., 2008). Elevations in ILs are seen in the nocturnal hours and steadily drop through the night of normal sleep reaching their nadir in the morning hours around normal arousal (Motivala & Irwin, 2007). Older age was significantly associated with elevations in the cytokines in this study, which is an expected finding from the literature (Harris et al., 1999).

Serum IL-1ra and IL-6 levels were elevated during the waking hours of some of the caregivers of those with PMBTs. The average serum level for caregiver IL-1ra was within the normal range (< 500 pg/mL); however, a third of the caregivers had elevated serum levels within the moderate range with one outlier in the high range (> 3000 pg/mL) placing these caregivers at risk for inflammatory disorders (Elkayam, Yaron, Shirazi, Yaron, & Capsi, 2000; Meier et al., 2002). For 53.4% of the caregivers, serum levels of IL-6 were in the normal range (< 1.78 pg/mL); however, 25.3% had levels in the range for increased risk of cardiovascular disease and mortality (Danesh et al., 2008; Harris et al., 1999; Steptoe, Willemsen, Owen, Flower, & Mohamed-Ali, 2001; Volpato et al., 2001). Elevations in IL-1ra and IL-6 are also associated with diabetes (Fernandez-Real et al., 2001; Juge-Aubrey et al., 2003), obesity (Juge-Aubrey et al., 2003; Roytblat et al., 2000); depression (Kapismalis et al., 2008), and other inflammatory disorders (Motivala & Irwin, 2007).

An unexpected finding was the lack of association with any of the ILs with sleep loss variables. Others have reported increases in WASO being associated with higher IL-6 levels in dementia caregivers (Von Kanel et al., 2006); however, this was not supported in this study. Prather and colleagues (2009) found that as sleep debt accumulated there were elevations in IL-β, of which IL-1ra is its proxy, and IL-6. The sleep loss variables in this study were not associated with elevations in IL levels; however, this may be explained by the shorter duration of caregiving and sleep losses. Associations may be found in the later stages of caring for the person with the PMBT. Helping to improve sleep and reduce stress in caregivers of those with PMBTs may decrease the elevations in IL-1ra and IL-6 levels and lower the risk for cardiovascular diseases, diabetes, and other sequela associated with being in an inflammatory state. Caregivers in this study who had better sleep quality had higher levels of IL-1ra but not IL-6. The higher levels (398 pg/mL) were within the normal range for IL-1ra. However, those caregivers with poorer sleep quality had lower IL-1ra levels (298 pg/mL), which may place them at risk for infections (Prather et al., 2009).

Higher care recipient functioning and fewer caregiver comorbidities were associated with self-perceptions of better health. With the care recipient’s ability to care for his or her ADLs, caregivers may be able to attend to and maintain personal physical health, explaining the perceptions of better health. With higher physical functioning and the association of longer sleep times and less WASO, caregivers may be able to meet some of the restorative functions of sleep, which may also contribute to the perceptions of better personal health.

Neither the sleep deprivation and disruption variables of gender, employment status, caregiver stress, anxiety, or nicotine use nor the sleep loss variables of TST and sleep quality, contributed to any of the variance seen in the physical health of caregivers of persons with PMBTs. Gender and nicotine use may not have been significant in this study as the sample was fairly homogenous. The shortened caregiving time may help to explain why caregiver stress and anxiety about providing care or caregiver reactions to care recipient symptoms were not predictive at this point in the caregiving role. Although caregivers’ shortened TSTs and perceptions about sleep quality may not have influenced their physical health because of the short time in the caregiving role, as the tumor effects spread and the caregiving demands increase over time, the accumulation of sleep loss may be greater resulting in greater stress and more effects on the inflammatory response.

Predictors of cognitive/behavioral health. A small amount of variance in QOL was explained by caregiver anxiety, TST, WASO, and sleep quality. Those caregivers of persons with PMBTs who had higher anxiety, longer sleep times, and more WASO reported poorer QOL. These findings are consistent with the caregiver sleep literature in those caring for persons with dementia or cancer (Carter & Chang, 2000; Carter, 2006; Hamilton et al., 2007; Willette-Murphy et al., 2006). The caregivers of persons with PMBTs who experienced better sleep quality had better QOL. Cognitive effects including mood are made worse by sleep deprivation (Banks & Dinges, 2011), which may explain the poorer perceptions of QOL in those with greater WASO. The caregivers with higher anxiety reported poorer QOL than the caregivers with little anxiety. It is unclear what the nature of the anxiety is leading to poorer sleep quality found in the caregivers of persons with PMBTs.

Although higher caregiver anxiety and increased sleep time were associated with increased fatigue and less fatigue was associated with being a smoker and a positive caregiver reaction to the caregiving situation, none of these relationships were independent predictors of caregiver fatigue. There were few smokers in the study and the number may not have been adequate to detect relationships. Although not statistically significant, the associations are in the expected direction as the stimulation effect of nicotine may explain the feelings of less fatigue in smokers (smokers report a perceived state of energy after their first cigarette of the day; Adan, Prat, & Sanchez-Turet, 2004). Caregivers who have a positive reaction to the caregiving experience may perceive their energy levels as high and do not appraise the demands of caregiving negatively.

The sleep deprivation and disruption variables of age, gender, employment status, caregiver demands, and number of comorbidities were not significant contributors to the cognitive/behavioral health of caregivers of persons with PMBTs. With the higher physical functioning of the care recipient, caregiving demands at this point in the tumor trajectory may allow caregivers to cope and maintain their cognitive/behavioral health; however, as the care recipient’s tumor progresses, these findings may change as the care recipient’s physical functioning declines and the caregiver assumes more care and is faced with the loss of their family member.

Predictors of emotional health. Theorized predictors explained little variance in the depressive symptoms and spiritual health models respectively. Higher anxiety and caregivers who were smokers were associated with higher depressive symptoms. Depressive symptoms have consistently been associated with poor sleep as measured by TST, sleep latency, WASO, and sleep quality in the caregiving literature for caregivers of those with dementia and cancer (Breaudeau et al., 2008; Carter, 2005; Carter 2006; Castro et al., 2009; Kochar et al., 2007; Rowe et al., 2008; Rowe et al., 2010). In this study, approximately one third of caregivers of persons with PMBTs reported depressive symptoms, indicating possible clinical depression. The lack of associations between the sleep variables and depressive symptoms in this study was unexpected. One explanation may be that there has not been enough time to develop depressive symptoms suggestive of clinical depression associated with caregiving because of the short duration in the caregiving role and the lack of accumulation of chronic sleep debt. There is evidence that those who have shorter sleep times have a higher risk of developing major depressive disorder, particularly in females (Brooks et al., 2009; Swanson et al., 2010).

There is strong evidence that anxiety and depression are associated with poorer sleep (Berger et al., 2005; Brummett et al., 2006; Edell-Gustafsson et al., 2003; Kelly, 2003; McCurry et al., 2007; Vaz Fragoso & Gill, 2007). Consistent with these findings, anxiety was associated with depressive symptoms in caregivers of persons with PMBTs. Different from findings in previous studies (Haley, LaMonde, Han, Burton, & Schonwetter, 2003; Saunders, 2009; Valimaki, Vehvilainen-Julkunen, Pietila, & Pirttila, 2009), those caregivers of persons with PMBTs with higher depressive symptoms rated their QOL similar as those with lower depressive symptoms.

Relationships between smoking with depressive symptoms are not reported in the caregiving literature. However, nicotine use and its association with major depression have been well documented in the depression and addiction literature (Adan et al., 2004; Hebert, 2004; Lyons et al., 2008; Moreno-Coutino, Calderon-Ezquerro, & Drucker-Colin, 2007).

Higher anxiety and poorer sleep quality were predictors of less spiritual health. These are not primary relationships discussed within the caregiving sleep literature for dementia or cancer. Sanders et al. (2008) reported in their qualitative study of caregivers of those with dementia that spiritual faith was a coping strategy identified by this group of caregivers to cope with the high levels of grief, burden, and stress. Cohen, Yoon and Johnstone (2009) found in individuals with heterogeneous medical disorders that positive spiritual beliefs and congregational support were associated with better mental health more so than religious practices such as prayer. Thus, the use of faith and a faith community as a coping strategy may help ameliorate anxiety and in turn improve sleep quality; however, further research into this aspect of emotional health is needed. Additionally, if caregivers are anxious and perceive poor sleep quality, they may not be able to attend spiritual practices that might offer support. Fostering opportunities for caregiver participation in spiritual practices may be beneficial.

Neither the sleep deprivation and disruption variables of age, gender, employment status, care recipient physical functioning, and number of comorbidities nor TST nor WASO contributed to any of the variance seen in the cognitive/behavioral health models. As previously discussed, the homogeneity of this sample may account for the sleep deprivation and disruption variables and the nonsignificant findings in emotional health. Furthermore, as discussed above, the lack of association between TST and WASO with emotional health was unexpected. Further research of emotional health across the brain tumor trajectory is warranted.

Predictors of social health. Older age and the presence of more comorbidities were associated with more work limitations for those caregivers who were employed, which is an expected finding. Sleep loss variables were not associated with social support. In contrast, lack of social support was associated with poor sleep quality in caregivers of those with dementia (McCurry et al., 2007). It is well documented in the literature that caregivers who perceive strong social support cope better and report less stress (Caswell et al., 2003; Haley, Levine, Brown, & Bartolucci, 1987; Iecovich, 2008; Yee & Schulz, 2000). The majority of caregivers of persons with PMBTs reported feeling high levels of social support.

The lack of support for the hypotheses related to sleep deprivation, sleep disruption, and sleep loss variables highlights the multifaceted relationships and complexity of the caregiving context and caregiver health outcomes. No one sleep predictor explained large amounts of variance in the health dimensions. Sleep is a complex and multifaceted physiological state as is health, which underscores the need for further research into understanding the complex interactions between sleep and health.

Other Associations in the Sleep Impairment Model

In examining relationships between antecedents to sleep loss, there were other significant relationships among some of the sleep deprivation and sleep disruption variables and the sleep loss variables of TST, WASO, and sleep quality. Caregiver negative response to care recipient symptoms was associated with longer sleep latencies, which could shorten the caregiver nocturnal sleep period. There are no reports in the literature of associations between caregiver bother/demands and sleep loss variables other than Beaudreau et al. (2008) who found that negative responses to care recipient symptoms were not associated with sleep efficiency as measured by actigraphy in caregivers of those with dementia. An explanation for the longer sleep latencies may be that caregivers who are more stressed or bothered by care recipient symptoms may release a chemical cascade that stimulates the hypothalamic-pituitary-adrenal axis which increases energy, cardiovascular tone, and vigilance, making falling asleep difficult (Lee, 2003).

Another relationship seen in the sleep variables was that caregivers who were employed and experienced higher anxiety had more efficient sleep. As previously discussed, those with increased fatigue—whether from employment or anxiety—may experience a higher sleep propensity and, therefore, may sleep more efficiently to reduce sleep pressure. The effects of all of these sleep deprivation and disruption variables are cumulative, such that even mild reductions in sleep no matter the etiology, over a period of time, can result in significant functional deficits (Simpson & Dinges, 2007).

Within the caregiver health dimensions, there were small to large associations between some of the dimensions. Higher vitality was associated with better physical health, better QOL, more social support and less depressive symptoms. Stronger spiritual health and more social support were associated with better QOL as was stronger spiritual health with more social support, which is consistent with other caregiving literature where social support has been found to be associated with less depression (Haley et al., 2003). This finding reinforces the need to discuss with caregivers the importance of seeking social support during this difficult time. Because the caregivers of persons with PMBTs reported poorer QOL, support for their spiritual practices, social support, and finding ways to lower fatigue as indicated by the reported associations may help to improve QOL in these caregivers.

Limitations of the Study

Limitations of the study must be examined when considering the outcomes of the findings. The parent study focused on caregiver psycho-behavioral responses, biological responses, and overall health changes from diagnosis to 12 months after diagnosis of those with PMBTs and was not specifically targeting sleep as a primary outcome. In a study specifically addressing sleep, using valid and reliable sleep questionnaires such as the entire Pittsburgh Sleep Quality Index or the Epworth Sleepiness Scale may be helpful to better examine sleep. The Epworth Sleepiness Scale examines daytime sleepiness as a trait component and assumes that a person can remember dozing in different types of activities. Daytime sleepiness is considered a reflection of poor nocturnal sleep (Johns, 1991).

The accelerometers worn for objective sleep measurements varied in length among the participants although they were asked to be worn for 3 full days. In the sleep literature, it is recommended for accelerometers to be worn for a minimum of 5 days (Acebo & LeBourgeois, 2006; Morgenthaler et al., 2007) to provide a clearer representation of the participants sleep pattern and increase the reliability of sleep variables collected from the accelerometers. In this sample, most wore their accelerometer for a minimum of 2 nights. It is unclear why participants did not wear the accelerometer for the desired three nights. Future studies should include phone follow up to assess for burden or to remind the caregiver to wear the device. Although participants were asked to annotate their activities in a diary, annotations were inconsistent across the participants, making it more difficult to ascertain periods of inactivity from periods of sleep. This lack of notation made it difficult to validate the findings from the accelerometer. This limitation was managed in data analysis in part by designating a time frame in which to examine sleep and to define sleep as a period of 30 minutes or more where the accelerometer was registering the participant as asleep.

Although day of the week could be determined from the accelerometers, diary notations would have been helpful in determining whether the accelerometer was being worn during a typical workday for those caregivers who were employed, adding to the knowledge of the stressors experienced by those providing care and managing employment situations. Other information that could help examine sleep from the diaries could include information about the individuals TST preference, sleep environment, pre-sleep habits, caregiving activities in the night, and so forth. With younger female caregivers within the data set, diaries would be helpful in discerning hormonal influences upon sleep. All of these variables could potentially confound or moderate relationships among sleep variables.

Another instrumental threat to the internal validity of this study included the inability of the Bodymedia® Sensewear™ Armband to detect wake episodes of less than t10 minutes. This limitation may have led to overestimation of the TST and underestimation of the WASO; however, having 118 participants' accelerometer data for a minimum of 2 nights should have helped to minimize the threat to the validity and reliability of the TST and WASO calculations.

Specimen collection times may have influenced the detected levels of IL-1ra and IL-6. Although the specimens were immediately placed on ice after blood draw, the time of day varied for the actual draw based on when the caregiver could meet with the research assistant. Although all draws were completed during day light hours, some were in the morning and others in the afternoon. As the nocturnal period approaches, IL levels begin to rise, helping to initiate sleep. This variability in timing may have decreased the internal validity of the serum blood draws. With the sampling of 104 caregivers, this threat should have been minimized statistically.

The current study was limited to the variables that were collected by the parent study, which is a limitation of secondary data analysis. Other instruments used in caregiving populations to measure concepts may have been selected to facilitate comparison to other research in caregivers and sleep. For example, daytime sleepiness, a reflection of fatigue related to sleep loss, could have been measured using the Epworth Sleepiness Scale similar to Castro et al. (2009) and Fonareva et al. (2011). Overall sleep quality is measured in several caregiving studies using the Pittsburgh Sleep Quality Index (Carter, 2005; Carter, 2006; Castro et al., 2009; Fonareva et al., 2011).

Strengths of the Study

This study used a well-established sleep impairment model to examine health outcomes related to sleep. Furthermore, there were 133 caregivers in the study, which provided appropriate statistical power to examine most study hypotheses; however, there were missing data on some variables. This secondary analysis provided an unique opportunity to examine this caregiving population since PMBTs are a rare cancer, accounting for only 1.5% of all cancers. Although there is some limitation of the accelerometer and serum blood draw measurement, the use of objective and subjective measures to examine some of the sleep and health variables added to the validity and reliability of the research design.

Implications for Practice

Ideally, using family centered care, health care providers address both care recipient and caregiver issues in their interactions with the dyads when encountered in the acute care and clinic settings. However, this is not always the reality of practice and may be particularly evident in care related to persons with PMBTs. Many care recipients are not ill enough to be hospitalized or seen on a regular basis in the clinic setting after initial diagnosis and debulking of the tumor. Much of the contact with health care occurs in a radiation center in which the caregiver may never see health care providers as they are often asked to wait in the waiting room. Health care practitioners need to be aware of caregiver needs and make time to address caregivers as well when seeing the care recipient.

As the caregiver must assume care for the person with a PMBT, it is important for health care providers to be educated about the effects of sleep impairments on caregivers' health. Assessing anxiety and addressing ways to decrease it should be included in contacts with caregivers. Anxiety and its role on sleep must be emphasized in order to ameliorate the effects on depressive symptoms. Those with high anxiety have poorer sleep quality. This perception of poor sleep may affect the caregiver's stress levels and stimulate the HPA axis which leads to longer sleep latencies and difficulty maintaining sleep. This may lead to shorter sleep times, which are associated with an increased risk of depression. Furthermore, poor sleep quality is associated with impaired cognition and short term memory, hence health care providers need to include written information along with verbal information when providing education to caregivers. An emphasis on anxiety reduction, which may improve sleep quality, may also improve QOL for these caregivers. Nurses or other health care professionals may discuss with the caregiver the upcoming demands and the need for caregivers to take care of themselves, including getting sufficient sleep.

For caregivers who are not anxious, nurses need to be aware of their sleep patterns as well. Those who were not anxious is this study had a higher number of WASO episodes. This fragmentation of sleep contributes to poor sleep quality and the deficits mentioned above. To simply ask a caregiver about his or her sleep is not enough. As shown by the objective and subjective measures of this study, caregivers underestimated their sleep latency and WASO. Written information about sleep and ways to improve sleep quality are needed for these caregivers.

Information about sleep habits and practices to improve sleep should be a part of the teaching information. Information such as (a) going to bed and arising at the same time each day and (b) avoiding heavy meals; extreme exercise; or alcohol, caffeine, or nicotine before laying down to sleep (AASM, 2010; Mastin, Bryson, & Corwyn, 2006; Qidwai, Baqir, Baqir & Zehra, 2010). Other teaching points include (a) avoiding watching television or engaging in other activities that wake the person up, such as internet games, video games, or cleaning house and (b) assessing the sleep environment for loud noises, bright lights, or other distractions such as pets (AASM, 2010; Mastin et al., 2006; Qidwai et al., 2010). If the caregiver has trouble falling asleep, he or she should be advised to get out of bed after 20 minutes and try again when they feel sleepy (AASM, 2010; Berger et al., 2009). For those caregivers with shortened TSTs, taking a nap during the day that is limited to 30 to 45 minutes (AASM, 2010; Berger et al., 2009) may help with the impairments of poor sleep.

Although other significant predictors were identified in the study, anxiety, consistently in this study, was associated with sleep or health outcomes whether positively or negatively. With the limited amount of time that nurses have contact with these caregivers, maximizing interaction is important. A brief assessment of caregiver anxiety and sleep, teaching caregivers to cope with anxiety, or making referrals when appropriate for counseling could go a long way in preserving or improving the health, which includes QOL, of caregivers of those with PMBTs.

Recommendations for Future Research

This study's findings suggest the need for further research. Sleep for caregivers at time of diagnosis of the PMBT was impaired. However, it is unknown whether these impairments seen at baseline continue, worsen, or become better during the caregiving experience. Observations (a) of sleep loss, and of sleep deprivation and disruption variables and (b) of their impact on caregiver health across the trajectory of caring for the person with a brain tumor is warranted, particularly as research has shown that those with shortened TSTs have a higher risk of developing depression (Sculthrope & Douglass, 2010). Approximately one third of caregivers of persons with PMBTs had higher depressive symptom scores, suggestive of a need for a referral for screening for clinical depression, and had significantly shorter sleep time than the 7 hours recommended by AASM (2010).

The caregivers with higher depressive scores also tended to be those caregivers experiencing anxiety. Whether this anxiety (a) ameliorates with caregiving experience or (b) changes as the tumor changes and care recipient function deteriorates is unknown. Similarly, the relationship between anxiety and sleep is unknown. Currently, in the trajectory of caregivers of persons with PMBTs, it is unknown in this population whether sleep changes return to prediagnosis levels or continue during the bereavement period like Carter (2005, 2006) found in her studies of bereaved caregivers of those with cancer.

Lastly, in extending the research in this population of caregivers of those with PMBTs, primary studies that specifically address sleep are needed. Instruments designed to assess sleep, both objective and subjective, need to be included in future research. Future research needs to follow the recommendations for objective sleep measurement through the use of devices designed to measure sleep specifically for five full 24-hour periods coupled with diaries and research assistants who follow the participants daily to encourage accuracy in the data collection. Well-established subjective measures of sleep should be used as well. Obtaining information about known sleep history of sleep problems would be important in the initial assessment. Open-ended questions about sleep prior to the diagnosis would aid in determining whether sleep impairments were new in nature or a continuation of previous sleep issues. By examining sleep throughout the continuum of care, specific interventions could be developed and tested.

Conclusion

Caregivers of those with PMBTs experienced sleep impairments. Sleep impairments included shorter TST, delayed sleep latencies, and a greater percentage of WASO episodes, which were significantly different than the general population. Over half of the caregivers (57.9%) experienced sleep latencies of greater than 15 minutes, 63.9% experienced sleep times less than 7 hours, and 56.4% experienced WASOs above the average of 10%. More than half of the caregivers in this study reported high levels of anxiety that were associated with poorer sleep quality and more depressive symptoms.

These caregivers also reported poorer QOL. Sleep impairments place caregivers of those with PMBTs at risk for future health problems, both physically and mentally. Further research is needed within this caregiver population to confirm these findings and to determine if sleep loss and caregiver health improves or worsens along the caregiving trajectory.

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APPENDIX A

VARIABLES AND INSTRUMENTS FOR CAREGIVER STUDY

Table A1

Variables and Instruments for Caregiver Study

Variable	Instrument	Source of data from original study
Adverse outcomes related to sleep loss		
Physiological domain		
Altered immune function	IL-1ra and IL-6 levels	Serum blood draw
Poorer physical health	Physical Health of MOS SF-36	Caregiver
Cognitive/behavioral domain		
Fatigue	Vitality of MOS SF-36	Caregiver
Overall QOL	FSQOL	Caregiver
Emotional domain		
Depression	CES-D	Caregiver
Less spiritual well-being	FACIT-sp	Caregiver
Social domain		
Social support	ISEL	Caregiver
Work limitations	WLQ	Caregiver
Sleep loss		
TST	TIB- total minutes of awake time	Accelerometer
WASO	(1- TST/TIB - sleep latency) x 100%	Accelerometer
Sleep quality[a]	Single-item subscale of PSQI	Caregiver
Additional measures of sleep		
Sleep efficiency	100% - WASO	Accelerometer

Variable	Instrument	Source of data from original study
Sleep onset latency	Lights out - sleep onset	Accelerometer
Sleep/wake cycle	Sleep onset, sleep arousal for each day	Accelerometer
Sleep deprivation		
Demands of caregiving		
Response to care recipient symptoms	MDASI-BT	Caregiver
Care recipient physical function	Karnofsky Score	Caregiver
Age	Demographics	Caregiver
Gender	Demographics	Caregiver
Employment	Demographics	Caregiver
Sleep Disruption		
Stress of caregiving	CRA	Caregiver
Anxiety	POMS-Anxiety	Caregiver
Nicotine use	Demographics	Caregiver
Health conditions/comorbidities	Summed general health conditions	Caregiver
Care recipient characteristics	Demographics	Care recipient medical record

Note. IL = interleukin; QOL = quality of life; TST = total sleep time; WASO = wake after sleep onset; FSQOL = Fox Simple Quality of Life; CES-D = Center for Epidemiologic Studies-Depression Scale; FACIT-Sp = Functional Assessment of Chronic Illness Therapy- Spiritual; ISEL = Interpersonal Support Evaluation List; WLQ = Work Limitations Questionnaire; TIB = time in bed; PSQI = Pittsburgh Sleep Quality Index; MDASI= M.D. Anderson Symptom Inventory; KPS = Karnofsky Performance Scale; POMS = Profile of Mood States; BMI = body mass index

[a] Item from Pittsburgh Sleep Quality Index.

APPENDIX B

INTERLEUKIN (IL-1 AND 1L-6) POLICY FROM PARENT STUDY

Interleukin (Il-1 and Il-6) Policy

All blood draws will be done by the interviewer trained in phlebotomy or principal investigator and will be processed by a research team member who has complete proper laboratory and blood borne pathogens trainings. Interviewers will confirm that caregivers have not smoked or ingested caffeine for at least one-half hour prior to blood collection. Phlebotomist (interviewer or principal investigator) will draw four 5ml EDTA tubes from the caregiver at the end of the home visit.

Interleukin analysis

1. Processing of blood will occur in a laboratory on the 4th floor of Victoria Building.
2. Use of Biological Safety Cabinets will follow attached protocol.
3. Use of PPE: gloves, lab coat/gown, glasses, and face mask is to be utilized at all times when working with specimens in the lab.
4. Within 30 minutes of the blood draw, tubes will be centrifuged at 1100 rpm for 10 minutes and the plasma will be drawn off in 1ml increments.
5. Place? pipette, white box, and vial holder on work surface.
6. Draw off 1mL increments of plasma per protocol using cryo-tubes, using aseptic technique.
7. Cap tubes.
8. 1 ml specimen containers will be labeled with the study, study ID number, time point (A=baseline, B=4 months, C=8 months, D=12 months), date, and time (using military time); e.g. **‘BTCG – 001A – 6/24/05 – 1600’** for study participant #1 at baseline.
9. When finished with analysis, place specimens in white container for transport to freezer.
10. Discard empty blood collection tubes into beige container to be autoclaved at a later time.
11. Disinfect vial holder by spraying with 10% bleach solution. Wait 10 minutes and then apply DNA Away. Allow to dry on blue disposable sheet.

12. Remove Biological Waste and Liquid Biological Waste from hood. Place waste in appropriate receptacle. (See attached)
13. Labeled 1ml specimen containers will be placed in a small white box labeled **‘Sherwood Cgvr study’** and placed in a freezer in the School of Nursing.
14. Freeze the tubes at –80ºC.

APPENDIX C

INSTRUCTIONS FOR BODYMEDIA® SENSEWEAR™ ARMBANDS FOR CAREGIVERS FROM PARENT STUDY

Monitoring Your Energy Expenditure

Please call the project office toll free at 866-834-5447 with any problems or concerns. Thank you again for taking the time to share your experience with us. What you share with us gives us the tools we need to help future caregivers.

1. Please wear the armband for three full days. You should wear the armband while you are awake, sleeping, exercising, and doing your normal routine. Please do not wear the armband while you are showering.
2. Please write down your general activities on the activity record sheet we gave you and either mail it back to us or bring it in to the clinic when you see us. You do not need to write down everything you do --just give us a general idea (for example, 8-11 ‘Ran errands’ or 2-3 ‘Went jogging’).
3. Place the armband on your upper arm. You can use either arm whichever is more comfortable for you, **but please use the same arm for all three days.**
4. The plastic part of the armband should be on your tricep -- on the outer part of your arm.
5. Secure the Velcro strap so that the armband is secure but not too tight. It is okay to adjust the armband throughout the day to keep it comfortable.
6. If the armband starts to beep, please call the project office. The green light on the armband will blink on and off.
7. When three days is over, please mail the armband along with the blood pressure monitor to the project office using the box we provided (you can drop it in any post office box).

APPENDIX D

FULL HIERARCHICAL REGRESSION MODELS FOR HYPOTHESES 1 - 5

Hypothesis 1: *Sleep deprivation factors (caregiving demands, a reflection of care recipient function, care recipient physical function, and employment) and sleep disruption factors (stress, anxiety, nicotine use, and health conditions) will contribute significant variance (p < .05) to sleep loss (TST, WASO, and sleep conditions) while controlling for age and gender.*

Table D1

Hierarchical Regression Analyses Predicting Sleep Loss with Sleep Deprivation and Sleep Disruption Variables

	Sleep loss variable					
	TST		WASO		Sleep quality[a]	
Predictor	ΔR^2	β	ΔR^2	β	ΔR^2	β
Step 1						
Control variables[b]	.05		.00		.01	
Step 2 (deprivation)	.05		.09		.12	
Caregiver bother		-.15		.02		.13
Karnofsky score		.02		-.10		.32
Employment status		.23		-.28		-.05
Step 3 (disruption)	.22*		.09		.19*	
CRA		.12		-.16		-.13
POMS-Anxiety		.44**		-.20		.38**
Smoking status		-.21		.12		.07
Comorbidities		.03		-.17		-.17
Total R^2	.32*		.18		.32*	
n	51		45		54	

Note. TST = total sleep time; WASO = wake after sleep onset; CRA = Caregiver Reaction Assessment; POMS = Profile of Mood States.
[a] Sleep quality item from Pittsburgh Sleep Quality Index. [b] Control variables include age and gender.
* $p < .05$. ** $p < .01$.

Hypothesis 2: *Sleep deprivation factors (caregiving demands, a reflection of care recipient function, care recipient physical function, and employment), sleep disruption factors (stress, anxiety, nicotine use, and health conditions), and sleep loss (TST, WASO, and sleep quality) will contribute significant variance (p < .05) to adverse physiological health outcomes (altered immune function [increased serum levels of Interleukin 1 and Interleukin 6] and poorer physical health) while controlling for caregiver age and gender.*

Table D2

Hierarchical Regression Analyses Predicting Health Outcomes in the Physiological Dimension with Sleep Deprivation, Sleep Disruption, and Sleep Loss Variables

	Health outcome: Physiological					
	IL-1ra		IL-6		Physical health	
Predictor	ΔR^2	β	ΔR^2	β	ΔR^2	β
Step 1						
Control variables[a]	.13		.22*		.05	
Step 2 (deprivation)	.05		.07		.01	
Caregiver bother		-.04		.00		-.10
Karnofsky score		.19		.03		.04
Employment status		-.04		-.13		.03
Step 3 (disruption)	.12		.01		.30*	
CRA		.06		.05		-.07
POMS-Anxiety		.33		.10		.37*
Smoking status		-.08		-.11		-.16
Comorbidities		.11		.01		-.63**
Step 4 (sleep loss)	.02		.14		.11	
TST		-.15		-.26		-.25
WASO		-.14		.26		-.19

	Health outcome: Physiological					
	IL-1ra		IL-6		Physical health	
Predictor	ΔR^2	β	ΔR^2	β	ΔR^2	β
Step 4 (sleep loss)						
Sleep quality[b]		.11		.08		-.31*
Total R^2	.32		.44		.47*	
n	38		39		49	

Note. IL = Interleukin; TST = total sleep time; WASO = wake after sleep onset; CRA = Caregiver Reaction Assessment; POMS = Profile of Mood States.
[a] Control variables include age and gender. [b]Item from Pittsburgh Sleep Quality Index.
* $p < .05$. ** $p < .01$.

Hypothesis 3: *Sleep deprivation factors (caregiving demands, a reflection of care recipient function, care recipient physical function, and employment), sleep disruption factors (stress, anxiety, nicotine use, and health conditions), and sleep loss (TST, WASO, and sleep quality) will contribute significant variance (p < .05) to adverse cognitive/behavioral outcomes (higher fatigue and poorer overall quality of life) while controlling for caregiver age and gender.*

Table D3

Hierarchical Regression Analyses Predicting Health Outcomes in the Cognitive/Behavioral Dimension with Sleep Deprivation, Sleep Disruption, and Sleep Loss Variables

	Health outcomes: Cognitive/Behavioral			
	Vitality		Quality of life	
Predictor	ΔR^2	β	ΔR^2	β
Step 1				
Control variables[a]	.02		.10	
Step 2 (deprivation)	.01		.09	

	Health outcomes: Cognitive/Behavioral			
	Vitality		Quality of life	
Predictor	ΔR^2	β	ΔR^2	β
Step 2 (deprivation)				
Caregiver bother		.05		-.04
Karnofsky score		.06		-.05
Employment status		.01		-.21
Step 3 (disruption)	.11		.21*	
CRA		-.02		-.13
POMS-Anxiety		-.13		-.16
Smoking status		.16		-.32
Comorbidities		-.14		-.28
Step 4 (sleep loss)	.09		.10	
TST		-.41		-.14
WASO		-.32		-.08
Sleep quality[b]		.08		-.46*
Total R^2	.24		.51*	
n	47		41	

Note. CRA = Caregiver Reaction Assessment; POMS = Profile of Mood States; TST = total sleep time; WASO = wake after sleep onset.
[a] Control variables include age and gender. [b]Item from Pittsburgh Sleep Quality Index.
* $p < .05$. ** $p < .01$.

Hypothesis 4: *Sleep deprivation factors (caregiving demands, a reflection of care recipient function, care recipient physical function, and employment), sleep disruption factors (stress, anxiety, nicotine use, and health conditions), and sleep loss (TST, WASO, and sleep quality) will contribute significant variance (p < .05) to adverse emotional outcomes (higher depression and lower spiritual well-being) while controlling for caregiver age and gender.*

Table D4

Hierarchical Regression Analyses Predicting Health Outcomes in the Emotional Dimension with Sleep Deprivation, Sleep Disruption, and Sleep Loss Variables

	Health outcomes: Emotional			
	Depression		Spiritual health	
Predictor	ΔR^2	β	ΔR^2	β
Step 1				
Control variables[a]	.01		.04	
Step 2 (deprivation)	.02		.10	
Caregiver bother		.05		-.23
Karnofsky score		-.08		.30
Employment status		.10		-.04
Step 3 (disruption)	.10		.09	
CRA		.20		-.09
POMS-Anxiety		.29		-.32
Smoking status		.18		-.10
Comorbidities		-.06		.07
Step 4 (sleep loss)	.05		.00	
TST		.20		.05
WASO		.28		.08
Sleep quality[b]		-.11		.00
Total R^2	.18		.24	
n	46		45	

Note. CRA = Caregiver Reaction Assessment; POMS = Profile of Mood States; TST = total sleep time; WASO = wake after sleep onset.
[a] Control variables include age and gender. [b] Item from Pittsburgh Sleep Quality Index.
* $p < .05$. **$p < .01$.

Hypothesis 5: *Sleep deprivation factors (caregiving demands, a reflection of care recipient function, care recipient physical function, and employment), sleep disruption factors (stress, anxiety, nicotine use, and health conditions), and sleep loss (TST, WASO, and sleep quality) will contribute significant variance (p < .05) to adverse social outcomes (poorer social interactions and poorer work interactions for those caregivers who are employed) while controlling for caregiver age and gender.*

Table D5

Hierarchical Regression Analyses Predicting Health Outcomes in the Social Dimension with Sleep Deprivation, Sleep Disruption, and Sleep Loss Variables

	Health outcomes: Social			
	Social support		Work limiations	
Predictor	ΔR^2	β	ΔR^2	β
Step 1				
Control variables[a]	.14*		.10	
Step 2 (deprivation)	.01		.15	
Caregiver bother		-.08		-.15
Karnofsky score		.18		.01
Employment status		.01		.40
Step 3 (disruption)	.12		.44*	
CRA		.12		-.20
POMS-Anxiety		-.12		.60
Smoking status		-.24		.07
Comorbidities		.03		.38
Step 4 (sleep loss)	.12		.04	
TST		-.43*		.02
WASO		.05		.13

	Health outcomes: Social			
	Social support		Work limiations	
Predictor	ΔR^2	β	ΔR^2	β
Step 4 (sleep loss)				
Sleep quality[b]		.08		-.47
Total R^2	.38		.74	
n	46		19	

Note. CRA = Caregiver Reaction Assessment; POMS = Profile of Mood States; TST = total sleep time; WASO = wake after sleep onset.

[a] Control variables include age and gender. [b] Item from Pittsburgh Sleep Quality Index.

* $p < .05$. ** $p < .01$.

APPENDIX E

SLEEP VARIABLES OF SLEEP LATENCY, TST, AND WASO FOR CAREGIVERS OF PERSONS WITH PMBTS AS COMPARED TO SELECT CAREGIVING STUDIES

Table E1

Sleep Variables of Sleep Latency, TST, and WASO for Caregivers of Persons with PMBTs as Compared to Select Caregiving Studies

				Sleep latency (minutes)		TST (minutes)		WASO (%)	
Study	*N*	Type	Method of measurement	*M*	*t* test	*M*	*t* test	*M*	*t* test
Pawl (2011)	133	PMBT	Accelerometer	35		357		15.1	
Beaudreau et al. (2008)	60	Female, dementia	Actigraphy	24.5**	*t* = -3.24, *p* = .002	323**	*t* = 4.24, *p* < .001	34.7**	*t* = 22.58, *p* < .001
Carter (2005)	9	Bereaved cancer	Self-report	37	*t* = 0.63, *p* = .527	260**	*t* = 12.19, *p* < .001		-----
Carter (2006)	15	Bereaved, cancer	Actigraphy	11.1**	*t* = -7.39, *p* < .001	330**	*t* = 3.36, *p* = .001	13.6	*t* = 1.70, *p* = .093
Castro et al. (2009)	9	Female, dementia	Home PSG	19.8**	*t* = 4.69, *p* < .001	341.9	*t* = 1.86, *p* = .066	19.7**	*t* = 5.32, *p* < .001
Fonareva et al. (2011)	20	Dementia	Home PSG	17.3**	*t* = 5.46, *p* < .001	409.5**	*t* = 6.68, *p* < .001	13.1*	*t* = 2.27, *p* = .025
Rowe et al. (2008)	31	Older, dementia	Actigraphy	22.8**	*t* = -.3.76, *p* < .001	395.2**	*t* = 4.87, *p* < .001	12.3**	*t* = 3.19, *p* = .002
Rowe et al. (2010)	27	Dementia	Actigraphy	25.3**	*t* = -2.98, *p* = .004	390.7**	*t* = 4.31, *p* < .001	13.0*	*t* = 2.39, *p* = .019

Note. TST = total sleep time; WASO = wake after sleep onset.
*p < .05, **p < .01.