

SLEEP DISTURBANCE IN FAMILY CAREGIVERS  
OF COMMUNITY-DWELLING ADVANCED CANCER PATIENTS

BY

BRENDA HEARSON

A Thesis  
Submitted to the Faculty of Graduate Studies  
In partial Fulfilment of the Requirements  
For the Degree of

MASTER OF NURSING

Faculty of Nursing  
University of Manitoba  
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**NANCY BRENDA HEARSON**

**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University of  
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## ABSTRACT

The experience of caring for a terminally ill loved one at home is reported to be stressful and tiring. The disrupted sleep family caregivers experience when providing round-the-clock care may contribute to their stress and exhaustion. Limited research has addressed sleep disturbance in family caregivers providing palliative home care. Therefore, the purpose of this study was to examine and describe the experience of sleep disturbance in family caregivers (N=13) of advanced cancer patients living in rural and urban Manitoba. Qualitative and quantitative approaches created a rich data set from which to better understand this issue. Face-to-face interviews were conducted with each participant utilizing a semi-structured interview guide and analyzed using content analysis. Validated self-report research instruments, the Epworth Sleepiness Scale (ESS) and Pittsburgh Sleep Quality Index (PSQI), generated quantitative scores, along with the objective measurement of caregivers' sleep/wake patterns over 72 hours via actigraphy.

The overarching theme which emerged from the family caregivers narratives was 'Sleeping with One Eye Open.' The vigilant nature of caregivers' sleep was described as light and fragmented as opposed to deep and restorative. The sub-themes which emerged throughout the interviews encompassed the factors contributing to sleep disturbance, the consequences of sleep disturbance, and strategies identified by caregivers to overcome disturbed sleep. Based on the results of the ESS, five of the thirteen family caregivers (38.5%) had a score  $\geq 11$ , indicative of excessive daytime sleepiness and all thirteen caregivers had a total sleep score  $\geq 5$  on PSQI, indicative of moderate to severe sleep problems. Actigraphy findings revealed that family caregivers' sleep varied greatly from one night to the next. Caregivers' estimated receiving less sleep per night (PSQI  $M = 5.31$  hours), than was objectively captured via actigraphy ( $M = 6.67$  hours per night). Caregivers identified various strategies they utilized to overcome sleep disturbance, but struggled to identify new ways for the health care system to help them deal with this consequence of caregiving. The study findings inform nursing interventions, which include impeccable, ongoing assessment of the patient's and family's sleep status, patient and family education regarding the importance of sleep, strategies to promote sleep, and sleep hygiene, and the development and coordination of respite services. Study findings also inform future research aimed at promoting family caregiver's sleep and well-being, as well as sustaining quality patient care.

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## CHAPTER 1

### INTRODUCTION TO THE STUDY

#### **Introduction**

This foundational chapter will set the stage for this research study. The statement of the problem will be presented, as well as the purpose of the study and the research questions. The author will outline the personal assumptions related to the topic that were identified prior to commencement of data collection and analysis. The chapter will also define the key terms used and the significance of the work undertaken.

#### **Statement of the Problem**

Adequate sleep is essential for health, well-being and optimal physical and cognitive functioning (Kryger, Roth, & Dement, 2005). It follows therefore, that inadequate sleep may lead to serious consequences (McCance & Huether, 2006). The experience of caring for a terminally-ill loved one at home, while rewarding, is also reported to be stressful and exhausting (Carter & Chang, 2000; Scott, 2001). The disrupted sleep patterns of family members that result from providing round-the-clock care to dying relatives may contribute to this stress and exhaustion. Advanced cancer patients frequently experience a constellation of complex physical symptoms and psychosocial issues at the end of life that are challenging to manage at home (Aranda & Hayman-White, 2001). This reality, coupled with the current trend of shifting palliative care from the hospital to the community setting (Chochinov & Kristjanson, 1998; McClement, 2001; Stajduhar, 2003) will see family members increasingly assuming responsibility for the provision of complex round-the-clock care. Thus the demands of

caregiving, with its attendant impact on the quantity and quality of family caregiver sleep (Carter, 2002), are not expected to abate any time soon.

In order to design interventions to help family caregivers experiencing sleep disturbance, the sleep disturbances of family caregivers must first be carefully examined and described. In particular, research is needed that: i) captures the nature of sleep disturbances family caregivers experience, ii) explicates the consequences of sleep disturbance on the caregiver and the care recipient, and; iii) accesses caregivers' perspectives regarding what approaches might be helpful in addressing sleep disturbances while providing care to a family member with advanced cancer (Carter & Chang, 2000; Lee, Cho, Miaskowski, & Dodd, 2004; Sela, Watanabe, & Nekolaichuk, 2005).

### **Purpose of the Study**

The overarching purpose of this study is to examine and describe the concept of sleep disturbance as experienced by family caregivers of advanced cancer patients living in the community with the objective of identifying potential interventions to alleviate these disturbances. The following research questions will be addressed:

- 1) How do family caregivers of community-dwelling advanced cancer patients describe their experience of sleep disturbance?
- 2) What is the objective portrayal of family caregivers' sleep disturbance as measured by actigraphy?
- 3) What factors do family caregivers identify as contributing to sleep disturbance?
- 4) What consequences do family caregivers identify that sleep disturbance has on their ability to carry out their caregiving role?

- 5) What consequences do family caregivers identify that sleep disturbance has on daily living and their own health and well-being?
- 6) What do family caregivers identify as being helpful in managing the sleep disturbances that they experience?

### **Assumptions**

Prior to a qualitative research study, it is critical that the researcher identify his or her thoughts and ideas related to the phenomena to be explored. The purpose of this activity is to raise one's awareness of preconceived beliefs. Once these beliefs are acknowledged they can be set aside, or bracketed, allowing the researcher to approach the topic openly and honestly. This pre-established frame of reference helps the researcher to differentiate between his or her own assumptions and the thoughts and perspectives of the study participants throughout the process of data collection and analysis, thereby preventing bias and increasing the rigour of study findings (Streubert-Speziale & Carpenter, 2007). Hence, the author acknowledged the following assumptions based on personal and professional experience prior to and throughout the study:

- 1) Family caregivers are able to articulate their caregiving experiences and needs.
- 2) Family caregivers hold valuable insights into what might be realistic intervention strategies; in other words, the most pragmatic and effective ways that services and resources could be developed to address family caregivers' sleep disturbance.
- 3) Family caregivers will identify with and participate in this research project, as it addresses a very real problem experienced in their day-to-day caregiving role and promises to inform future policy and service development.

4) However, since the role of providing care to someone who is dying from cancer in the community is stressful and tiring for family members, caregivers may be too tired and too busy to participate in the study (particularly the actigraphy and sleep log component).

5) Female caregivers may be more willing to share their experiences than male caregivers.

6) If the patient has uncontrolled symptoms and is not sleeping well, then it is likely that the caregiver will also be experiencing sleep problems.

### **Definition of Terms**

The following terms are used in this study and are defined as follows:

***Advanced cancer*** – refers to the phase of the illness continuum or trajectory when the disease has reoccurred, spread and/or is no longer responding to treatment, and the treatment options aimed at cure do not exist and the treatment options aimed at control are often limited. At this time palliative care becomes the focus of care (Ferrell & Coyle, 2006).

***Family caregiver*** - refers to the primary non-paid caregiver of the person living in the community with advanced cancer. In accordance with the Canadian Compassionate Care Benefits Program's expanded definition of family member (2006), this includes friends, neighbors, or others that 'seem like family' to the person who is ill, as well as relatives.

***Palliative care*** – the World Health Organization (2002) defines palliative care as an approach that improves the quality of life of patients *and their families* facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, which could be physical, psychosocial or spiritual.

**Respite care** – is defined as “complementary, flexible care in the home... with appropriate medical and nursing supports, offering parents or carers an interval of relief” (Judd, 1994, p. 218).

**Sleep disturbance** - refers to any change(s) in the caregiver’s normal sleep/wake pattern while committed to providing palliative home care for a family member with advanced cancer. This may include one or any combination of the following attributes: a) difficulty falling asleep (i.e., taking more than 15 minutes) at bedtime and /or following night-time provision of care, b) fragmented or interrupted sleep or difficulty maintaining sleep (waking more than twice during the night), c) early morning awakening, and d) not feeling refreshed in the morning, excessive daytime sleepiness, or inability to function effectively in the caregiving role (Hearson, in press).

**Sleep-related terms as defined by Vena, Parker, Cunningham, Clark, and McMillan (2004):**

**Actigraphy** – a wristwatch-sized accelerometer worn on the caregiver’s non-dominant wrist, which senses movement and provides an objective measurement of rest and activity patterns around the clock

**Excessive daytime sleepiness** - difficulty maintaining the alert-awake state (e.g. can’t stay awake when sedentary); most common consequence of poor or insufficient sleep

**Circadian rhythm** – an innate daily fluctuation of physiologic or behavioral functions, including sleep-wake states, generally tied to the 24-hour daily light-dark cycles

**NREM sleep** - non-rapid eye movement sleep divided into four stages (I - IV)

**REM sleep** – rapid eye movement sleep

**Sleep architecture** – the NREM and REM stages and cycles of sleep

***Sleep efficiency*** – the proportion of actual sleep time (i.e., total sleep time) during the night or sleep episode, divided by the total time spent in bed, and then multiplied by one hundred, to express as a percentage

***Sleep fragmentation*** – the number of times sleep is disrupted in the night, based on self-reports and actigraphy movement index

***Sleep hygiene*** – the conditions and practices that promote continuous and effective sleep

***Sleep onset*** - the onset of sleep defined as the first epoch of NREM- Stage I sleep

***Sleep latency*** – the time from lights out to sleep onset

***Sleep quality*** – the overall character of sleep, including quantity, frequency of disturbances, use of medication, and daytime sleepiness and functioning

***Total sleep time*** – also known as sleep duration, this refers to the amount of actual sleep time in a night (or sleep episode) expressed in hours; the time is equal to the total time in bed (or sleep episode) less the awake time

***Wake time after sleep onset (WASO)*** – the total time the person is awake after falling asleep (sleep onset) at bedtime and before morning awakening

### **Significance of the Work**

Research indicates that family units are assuming most of the responsibility for palliative caregiving (Williams, 2004). In the United States, it has been estimated that the care that informal caregivers provide to terminally ill cancer patients is worth \$196 billion each year (Arno, Levine, & Memmott, 1999). Within the Canadian health care system, an estimated 80% of caregiving occurs in the home and is provided by unpaid family members (Stajduhar, 2003).

Although family members want to care for their family member at home, the responsibility is considerable and the work exhausting – both mentally and physically. Attaining adequate sleep is critical in maintaining the health and well-being of family members as they perform their caregiving role. As caregivers assume 24-hour care of palliative patients, the quality of their sleep is expected to influence their daily functioning, quality of life, mental, emotional and physical health, and bereavement processes (Carter, 2005; Riedel & Lichstein, 2000; Zammit, Weiner, Damato, Sillup, & McMillan, 1999). Thus, the impact of poor sleep in family caregivers is significant and far-reaching, and needs to be empirically examined from the perspective of caregivers themselves.

From a societal standpoint, providing home care is ultimately linked to the viability of our health care system. As the population ages and more cancer care is transferred to the community setting, interventions targeted at informal caregivers will be needed to ease the economic, psychological, and physical burdens of caregiving (Aranda & Hayman-White, 2001). Caregiver sleep disturbance emerges as one of the salient issues that must be addressed if we continue to expect family caregivers to assume major responsibility for in-home palliative care. Considering what is already known regarding the prevalence of sleep disturbance within patient and family caregiver populations, the consequences of poor sleep and the trends within our health care systems, it is critical and timely to extend our understanding of family caregiver sleep disturbance and the most effective ways for nurses to intervene (Hearson, in press-b). Impeccable assessment and effective intervention will benefit patients, caregivers and the health care system alike.

The results of this study will help clinicians, researchers, and educators better understand the nature of the sleep disturbances that family members experience in their caregiving role, and the contributing factors. The results will assist in designing palliative care programs which will support family members in their caregiving role. They will also provide direction in mounting intervention studies to promote sleep, health, well-being of family caregivers, and ultimately the care they provide to others.

### **Summary**

In summary, this foundational chapter has provided a statement of the problem, described the purpose of the study, outlined the research questions and provided definitions for the key terms utilized throughout. It has also identified the researcher's personal assumptions acknowledged at the onset of the study, and considered the significance of this research. The following chapter will review the current literature and consider the conceptual issues related to family caregiver sleep disturbance.

## CHAPTER 2

### REVIEW OF THE LITERATURE

#### **Introduction**

This chapter provides a synopsis of the literature review completed prior to the design of this research study. The topics addressed and summarized are sleep physiology and pathophysiology, the concept of sleep disturbance, and sleep disturbance in various patient and caregiver populations. These populations included patients with Alzheimer's Disease and their caregivers, patients with Parkinson's Disease and their caregivers, patients with advanced cancer, caregivers of cancer patients, and bereaved family caregivers. The chapter also contains a brief comparison of sleep disturbance across the various caregiving groups, as well as a summary of the cancer caregiver sleep intervention research to date, and the potential consequences of sleep disturbance in family caregivers.

This literature review included English language anecdotal reports, clinical papers, and research reports. Computerized data base searches, including Medline, CINAHL, PsycINFO, EMBASE-Psychiatry, UpToDate, MD-Consult and AMED, from 1995 to present day were conducted using the search terms sleep, sleep disturbance, sleep problems, sleep deprivation, sleep-disorders-circadian-rhythm, sleep physiology; caregiver(s), carer(s), family caregiver(s); cancer, advanced cancer, end-stage cancer, palliative care, end-of-life care; and consequences of disturbed or disrupted sleep. Current reference texts and reference lists from key articles were also reviewed with relevant citations retrieved. Given the limited amount of literature examining this topic,

the search was extended to examine articles about sleep disturbance in Alzheimer and Parkinson Disease patients and their caregivers.

Research to date provides insights regarding the prevalence and the etiology of sleep disturbances in patients with neurological diseases such as Parkinson's and Alzheimer's Disease. In contrast, limited empirical work has been conducted examining the specific issue of sleep disturbance in family members, especially in the context of their role in providing end-stage cancer care at home (Berger et al., 2005). Given that both the patient *and the family* constitute the unit of care in palliative care, this gap in our clinical knowledge is problematic, and warrants further investigation. The findings of this review will be presented by addressing the topics as outlined above.

### **Sleep Physiology**

“Sleep is a complex process and highly organized state that is fundamental to life” (Roehrs, 2000, p.1). Much remains unknown regarding the purpose and functions of sleep. However, it is generally understood that sleep serves a restorative function and is involved in the neurohormonal, thermoregulation and immune processes of the body (Kryger, Roth, & Dement, 2005). Sleep is regulated by the brain stem, thalamus, hypothalamus and external stimuli. The hypothalamus, known as the body's master switchboard for maintaining homeostasis, is referred to as the ‘sleep centre’ (McCance & Huether, 2006).

It is proposed that three distinct processes underlie sleep physiology: sleep homeostasis, circadian rhythm, and ultradian process (Kryger et al., 2005). Sleep homeostasis, the sleep-wake balance, is determined by the prior amount of sleep and waking. The circadian process is an internal, 24-hour clock-like mechanism controlled by

the circadian oscillator within the hypothalamus's suprachiasmatic nuclei. Rhythms are generated and synchronized with other body rhythms such as core body temperature and secretions of hormones, based on light and dark cues via the retinohypothalamic pathway. The ultradian process occurs within sleep and refers to the stages and cycles of sleep, commonly referred to as sleep architecture (Kryger et al., 2005). Normal sleep is structured with two phases: non-rapid eye movement (NREM) and rapid eye movement (REM). NREM is divided into four stages (I-IV) and represents approximately 75% of sleep. A typical night for a healthy young adult consists of four to six cycles of NREM and REM, with the REM stages increasing in length throughout the sleep period.

Numerous hormones and neurotransmitters are highly correlated with sleep and wake states. For example, melatonin is a sleep-inducing hormone secreted by the pineal gland during the absence of light signals from the retina (Sanna & Bruera, 2002); serotonin acts on multiple receptors in different cell types to attenuate cortical activation and facilitate the initiation of slow wave sleep; increased cortisol levels are associated with wakefulness; and the neurotransmitter, adenosine, accumulates in the brain during wakefulness and signals the need for sleep [note: caffeine blocks adenosine receptors]. The reticular formation, a complex system of neurons in the brainstem, is responsible for maintaining wakefulness and setting a particular threshold for arousal. The ability to be aroused from sleep is an important protective mechanism, which differentiates sleep from unconsciousness.

Lee (2003) indicates that normal sleep in healthy adults consists of falling asleep within 5 - 10 minutes, sleeping for 7 - 8 hours, and awakening refreshed and ready to perform their daily activities. Humans are considered monophasic sleepers, meaning that

our days are divided into two distinct periods of wakefulness and sleeping (National Sleep Foundation, [www.nationalsleepfoundation.org](http://www.nationalsleepfoundation.org). Retrieved May 2, 2007). Young children and the elderly are inclined to be polyphasic with short periods of sleep or naps throughout a 24-hour period. Napping is also important in some cultures. While naps do not necessarily make up for inadequate or poor quality nighttime sleep, a nap of at least 20 to 30 minutes can help to improve mood, alertness and performance (Kryger et al., 2005).

Normal sleep onset and maintenance depend on: an intact central nervous system, the timing of sleep within the 24-hour circadian rhythm, neurohormonal homeostasis, a conducive physical environment, optimum physical comfort, and minimal psychological distress (Sateia & Santulli, 2004). Factors that interfere with or enhance these conditions affect the quality and quantity of sleep and daytime wakefulness.

### **Conceptual Issues Related to Sleep Disturbance**

Scholars from a variety of disciplines such as nursing, medicine, psychiatry, psychology, physiology, neuroscience, endocrinology, and biology are engaged in sleep-related research, thus there are a myriad of ways in which sleep disturbance might be understood. Clarity and consistency in semantics is critical in the development of scientific nursing knowledge. Since conceptual definitions drive measurement decisions (Kristjanson, 1992), researchers must clearly define the phenomenon of interest. The majority of articles reviewed used, but failed to define the term 'sleep disturbance'. Where definitions were provided, sleep disturbance is understood as: any change(s) or variation(s) in the family caregiver's normal sleep pattern while providing palliative care to a family member who wishes to remain at home for as long as possible. Based on the

literature review, these changes or variations for a family caregiver may include, but are not be limited to, one or any combination of the following attributes: (a) difficulty falling asleep (taking more than 15 minutes); (b) fragmented or interrupted sleep or difficulty maintaining sleep (waking more than twice during the night); (c) early morning awakening; (d) not feeling refreshed in the morning, excessive daytime sleepiness, or inability to function in caregiving role (Berger et al., 2005; Carter, 2002; Lee et al., 2004).

Insomnia, a term closely related to sleep disturbance and used in the literature, is defined as repeated difficulty with sleep initiation, maintenance, or quality despite adequate time and opportunity for sleep, resulting in some form of daytime impairment (Kryger et al., 2005). Despite its many similarities to insomnia, sleep disturbance and insomnia are not interchangeable terms with respect to family caregiver sleep research. Family caregivers of end-stage cancer patients frequently do not have adequate opportunity for sleep. Even given the opportunity to sleep, caregivers sleep vigilantly, attuned and ready to respond to the patient. In anecdotal comments, family caregivers do not describe themselves as having insomnia. The majority of family caregivers are very committed to their caregiving role, willing to make the short-term self-sacrifices required to fulfill the wishes of the patient to stay at home, and knowing they have done their job well (Schumacher et al., 1998).

Other closely related terms are sleep deprivation, which results from an inadequate amount of sleep, or sleep disruption, which results from fragmented sleep during the night (Lee, 2003). While both of these realities may be experienced by

caregivers, these terms, on their own, may not fully embody the nature of sleep changes in the cancer caregiver population.

Sleep disturbance is an all-encompassing term used to describe complaints, symptoms or groups of symptoms experienced by individuals when a specific diagnosis is not yet or perhaps cannot be made (Berger et al., 2005). More importantly however, sleep disturbance, as a recognized nursing diagnosis (NANDA International, 2005), has the potential to be addressed through nursing interventions which can be evaluated in the context of randomized controlled trials.

### **Sleep Disturbance in Alzheimer's Disease Patients and their Caregivers**

Research indicates that while approximately 25% of individuals with Alzheimer's Disease experience sleep disturbance (Moran et al., 2005), over 60% of the family caregivers of individuals with Alzheimer's Disease experience sleep disturbances (McCurry & Teri, 1995). Caregivers witness and grieve the deterioration of a family member's mental, physical and social capacities, meanwhile assuming increasing responsibilities for assistance with activities of daily living, supervision, and safety around the clock. The impact of caregiving on sleep disturbance may be more profound for caregivers of those with Alzheimer's Disease who are themselves likely to be elderly (McKibbin et al., 2005; Willette-Murphy, Todero & Yeaworth, 2006).

Family caregivers of those living in the community with dementia demonstrate impairments across all sleep domains (sleep disturbance, quality, latency, duration, efficiency, daytime dysfunction), such that pharmaceutical intervention may be required. In a randomized controlled trial examining the benefits of a one-year exercise (vs. nutrition) intervention program for female caregivers (N = 90) of dementia patients, 38%

of caregivers reported periodic use of sleep medication to deal with sleep disturbances (Wilcox & King, 1999). Research also suggests that lack of sleep contributes to the caregiver's physical and psychological burden and is often cited as a reason for a family's decision to institutionalize a patient (McCurry & Teri, 1995; Moran et al., 2005).

### **Sleep Disturbance in Parkinson's Disease Patients and their Caregivers**

The prevalence of sleep disturbance in patients with Parkinson's Disease is estimated to range from 67 to 84%, and the prevalence of sleep disturbance in there is estimated at 39% (Pal et al., 2004). Research suggests that the severity of disease, medication, age, co-existing illness, anxiety and depression are factors influencing the prevalence and degree of sleep disturbance in these patients and caregivers (Thorpy & Alder, 2005). Studies demonstrate that the quality of sleep in those caring for individuals with Parkinson's Disease significantly correlates with the severity of the patients' motor function impairment, the patients' sleep disturbance, and the frequency of caregiving tasks (Happe & Berger, 2002; Pal et al., 2004).

A prospective study of patients with Parkinson's Disease ( $n = 40$ ) and their primary caregivers ( $n = 23$ ) revealed that 51% of patients demonstrated Zung's Self-Rating Depression Scale (ZDRS) scores indicative of pathological depression ( $> 50$ ) and that caregivers depression scores correlate positively ( $r = 0.6$ ;  $p < 0.01$ ) with the scores of the patients living with Parkinson's Disease (Pal et al., 2004). As well, sleep disturbance correlates positively with the severity of depression for patients ( $r = 0.6$ ;  $p < 0.01$ ) and caregivers ( $r = 0.6$ ;  $p < 0.01$ ). These findings underscore the need for optimal symptom management for the patient with Parkinson's Disease and other interventions that produce twice the effect - optimal sleep for the patient *and* caregiver. There appears to be

a close relationship between patient and caregiver sleep patterns, with potentially even greater sleep disturbance for the caregiver than the patient depending on the severity or care demands of the patient's illness.

### **Sleep Disturbance in Advanced Cancer Patients**

Studies conducted in the 1990's identified the existence of sleep problems for patients across the cancer trajectory from the time of diagnosis and treatment (Degner & Sloan, 1995; Engstrom et al., 1999). Thirty-one to seventy-five percent of cancer patients report problems sleeping at night, as well as daytime sleepiness. Literature to date has focused mainly on sleep problems earlier in the cancer disease trajectory rather than during the advanced stage of disease and palliative care (Lee et al., 2004). However, the limited work that has been conducted later in the disease process is instructive.

Miaskowski and Lee (1999) utilized wrist actigraphy to monitor the sleep-wake pattern of 24 adult out-patients receiving palliative radiation therapy for bone metastases. The findings revealed that  $70.7 \pm 22.4\%$  were awake on average 30% of the night in their home environment. Similarly, in a group of women with metastatic breast cancer (N = 97), 63% reported one or more problems related to sleep (Koopman et al., 2002). In a prospective audit involving cancer patients (N = 74) admitted to a hospice setting in the United Kingdom, 70% of the patients had insomnia and 60% of these patients cited uncontrolled symptoms as the cause (Hugel, Ellershaw, Cook, Skinner, & Irvine, 2004).

A descriptive correlational survey of 100 palliative oncology patients attending an out-patient symptom management cancer clinic in western Canada (Sela et al., 2005) asked: (a) how common is sleep disturbance? (b) how severe are the symptoms? (c) how does sleep difficulty relate to pain, fatigue, depression, and anxiety? (d) what are the

intervention choices and how effective are they? and (e) are patients communicating their sleep concerns and symptoms to health care providers? The majority of the participants (72%) reported that they experienced sleep disturbances. The most frequently reported attributes were: not feeling rested in the morning (72%), difficulty staying asleep (63%), and difficulty falling asleep (40%). These studies revealed that sleep disturbance is a significant and complex problem for advanced cancer patients.

### *Pathophysiology of Sleep in Advanced Cancer*

Pathology results when normal physiological functions weaken or change due to illness. Our understanding of the cause of sleep problems in advanced cancer is limited by the dearth of research in this population (Kvale & Shuster, 2006), yet the literature does offer some initial insights.

Advanced cancer patients may be at high risk for disrupted circadian function. It is reported that patients with metastatic colon cancer have a flattened rest-activity circadian rhythm (Mormont et al., 2000), and changes to the circadian cortisol rhythm have been identified in metastatic breast cancer patients (Sephton et al., 2000). In a study involving advanced lung cancer patients that examined circadian function, sleep quality, and levels of fatigue, Levin and colleagues (2005) concluded that the daily sleep and activity patterns of these patients were disrupted, resulting in decreased functional ability and quality of life.

The presence of malignant tumors, particularly those involving the respiratory and central nervous systems may lead to severe changes in the sleep processes (Sateia & Santulli, 2004). The general mechanisms of these changes include pressure, obstruction, invasion of sensitive structures, tissue destruction, and inflammation (McCance &

Huether, 2006). Sleep disorders have been reported at the time of diagnosis and following the surgical treatment of head and neck tumors (Rada, 2005). Primary or metastatic brain tumors may disrupt neurohormonal regulation of sleep as well as electroencephalography readings through all stages of sleep. Tumor growth involving the upper or lower respiratory system, as well as the muscle weakness associated with advanced disease, may lead to shortness of breath, sleep apnea, hypoxia, or hypercapnea, which may cause arousal and disrupt the sleep regulatory mechanism (Kryger et al., 2005; Vena et al., 2006). In a study that measured sleep subjectively and objectively in patients with various types of cancer (N = 982), Davidson and associates (2002) found that lung cancer patients have more problems with sleep than other cancer and healthy control groups.

Cancer disease may also alter hormone levels, thus interfering with sleep homeostasis. For example, the secretion of melatonin may be affected by brain tumors (Sanna & Bruera, 2002), while the body's intrinsic stress and immune response to a disease such as cancer causes escalating levels of cortisol (Kryger et al., 2005; McCance & Huether, 2006). Cytokines are naturally occurring molecules produced by white blood cells that provide signals to regulate immunological aspects of cell growth and function (McCance & Huether, 2006). Cytokines, such as interleukins, interferons, and tumor necrosis factor, are increasingly released by these immune cells during cancer growth at the cellular level. These cytokines exert their effect on the brain and peripheral nerves, activating the neurotransmitter responses of the brain. In turn the hypothalamic-pituitary-adrenal axis signals the release of corticosteroids, including cortisol.

The etiology of sleep disturbance in cancer patients appears to be multi-dimensional. Sleep disturbance may result from cancer disease, cancer-related stress,

cancer-related symptoms, and/or cancer treatment-related symptoms (Lee et al., 2004). It may develop across the cancer illness trajectory, with the potential to become chronic, or exacerbated by the increasingly complex symptoms experienced near the end of life. Although much remains unknown regarding the underlying pathophysiology of sleep disturbance in advanced cancer, it appears there is a multitude of better understood personal and environmental factors that combine into a pathological cocktail, resulting in disturbed sleep (Sanna & Bruera, 2002).

Personal and environmental factors may predispose, precipitate, or perpetuate sleep disturbance. Non-modifiable personal factors include age, gender, and a previous history of sleep disorders such as sleep apnea, narcolepsy, or restless leg syndrome (Savard & Morin, 2001). It is well-documented that sleep changes substantially and continuously across the lifespan, with approximately 30% of people over the age of 65 years reporting problems indicative of insomnia. Cancer is primarily a disease of the older population; in 2006 it is estimated that 43% of the new cases and 60% of the cancer-related deaths in Canada will occur among those over 70 years of age (<http://www.cancer.ca>. Retrieved November 24, 2006). Women are more prone to sleep problems than men (Kryger et al., 2005), which is echoed in the prevailing statistics of sleep disturbance in advanced cancer patients (Hugel et al., 2004).

A wide range of modifiable physical, psychosocial, and spiritual factors can influence the quality and quantity of sleep. Lifestyle factors such as diet, smoking, and coffee intake may contribute to difficulty sleeping. Sleep disturbance may also represent a secondary symptom to one of the many cancer-related symptoms (Sanna & Bruera, 2002). As mentioned earlier, a prospective audit of hospice patients (N = 74) admitted to

a palliative care setting found that 60% of the patients cited uncontrolled symptoms (Hugel et al., 2004), such as pain (Mercadante et al., 2004), depression (Sateia & Santulli, 2004) and anxiety (Hugel et al., 2004), as the cause of sleep disturbance.

Environmental factors include the side effects from treatments including surgery (Rada, 2005), chemotherapy (Lee et al., 2004), radiation (Miaskowski & Lee, 1999), or medication management (Mercadante et al., 2004). Other environmental factors include a change in setting or sleeping arrangements, extraneous light or noise perhaps from medical equipment such as an oxygen concentrator in the home, interruptions for round-the-clock caregiving, as well as changes in the patient's daily routine, such as less physical activity, stimulation, and fresh air (Sheely, 1996).

This is not an exhaustive discussion of the factors that may increase the palliative patient's vulnerability to sleep disturbance, nor has it addressed the important work to date related to symptom clusters which frequently include the symptom of sleep disturbance (i.e., the constellation of pain, fatigue, and sleep disturbance) (Beck et al., 2005). However, the association between sleep and a broad range of possible personal and environmental factors is abundantly clear.

Increased attention to the degree of sleep disturbance experienced by cancer patients has led to calls for improved ongoing assessment of cancer patients' sleep status, provision of patient-teaching materials on non-pharmacological approaches to facilitate sleep, and research programs aimed at better understanding the problem and its causes, and evaluating intervention strategies (Berger et al., 2005; Lee et al., 2004). In palliative care, it is presumed that if patients with advanced cancer are experiencing problems sleeping it is probable that their family caregivers are experiencing similar problems.

### **Sleep Disturbance in Cancer Caregivers**

There is a paucity of literature related to sleep disturbance experienced by family members early in the cancer caregiving trajectory. A recent study sought to examine the correlation between sleep quality and quality of life of caregivers of newly-diagnosed breast cancer patients (including only breast cancer stages 0-3) (Chang, Tsai, & Tsao, 2006). The findings revealed that 89% of the caregivers (N = 61, 59 male and 11 female, 42 of 61 were spouses) had global sleep scores on the Chinese Pittsburgh Sleep Quality Index (PSQI) greater than 5, indicative of significant sleep problems in two or more sleep components. The severity of sleep disturbance was also found to negatively predict quality of life, particularly in the physical health, psychological, social relationship and environmental domains.

In the palliative phase of the illness, numerous studies over the past two decades have explored the role, experiences, psychosocial impact, information and care needs of family caregivers of advanced cancer patients living in the community (Dunbrack, 2003; Hudson, 1998; Hudson, Aranda, & Kristjanson, 2004a; Hudson, Aranda, & Kristjanson, 2004b; Mangan, Taylor, Yabroff, Fleming & Ingham, 2003; Rose, 1999; Scott, Whyler, & Grant, 2001; Steele & Fitch, 1996). In recent years, research has begun to specifically address the concept of sleep disturbance in these caregivers.

The majority of work examining sleep disturbance in family caregivers of advanced cancer patients is reflected in the programmatic research conducted by Dr. Patricia Carter in the United States (2000, 2002, 2003, 2005, 2006). These studies on sleep disturbance in family caregivers of advanced cancer patients have primarily examined the correlation between caregiver sleep disturbance and depression. A cross-

sectional, descriptive survey (Carter & Chang, 2000) of 51 primary caregivers of community dwelling advanced cancer patients living in the southern United States used telephone and/or in-person interviews to administer the Center for Epidemiologic Studies – Depression Scale (CES-D) and the Pittsburgh Sleep Quality Index (PSQI). Results demonstrated that 95% of the caregivers experienced severe sleep problems and more than 50% exhibited symptoms at a level of risk for clinical depression. Correlations were strongest between caregiver depression and the sleep subscales of overall quality of sleep ( $r = 0.70; p < .001$ ), sleep efficiency ( $r = 0.70; p < .001$ ), and daytime dysfunction ( $r = .59; p < .001$ ). Results highlighted the need for longitudinal research to assess how caregiver variables change over time and to explore interventions that would allow caregivers to obtain the necessary sleep without diminishing their caregiving role (Carter & Chang, 2000).

A subsequent longitudinal pilot study conducted by Carter (2003) followed 10 adult family caregivers of cancer patients over a 10-week period. Sleep quality and depression were measured weekly and actigraphs were worn for 72-hour periods during Week 1, 5 and 10 of the project. The findings revealed that sleep and depression scores fluctuated greatly from week to week over the course of the study, and that “sleep quality and depressive symptoms were affected by several internal and external factors” (e.g., patient disease status, patient symptoms, and caregiver anxiety) (2003, p. 258). The study also demonstrated the utility of actigraphy as a data collection method to capture information beyond that of traditional self-report questionnaires. For example, the mean sleep duration for family caregivers calculated from the PSQI equaled 6.05 hours, while the mean sleep duration captured by actigraphy was 4.83 hours. This finding suggests

that caregivers tend to underestimate their sleep problems, and underscores the need for impeccable nursing assessment related to the caregiver sleep experience.

To further understand sleep changes and depressive symptoms experienced by family caregivers, Carter (2002) utilized caregiver narratives as well as quantitative scores generated from the CES-D and PSQI to triangulate research results. A total of 47 telephone or in-person interviews were conducted with caregivers of advanced-stage cancer patients living in the community. Caregiver narratives described the experience of progressive sleep deprivation that caused irritability, anger, guilt and depression, as well as an inability to provide care. These experiences were validated by quantitative data which revealed that 95% of the caregivers reported severe overall sleep problems and 57% scored at or above the standard population cut-point for the CES-D indicating that they were at risk for clinical depression. The caregivers reported moderate to severe sleep problems on six of the seven PSQI subscales (i.e. sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances and daytime dysfunction). Findings illuminated the impact of the caregiver's health and well-being on the patient's quality of care, especially in situations where patient needs are complex. Carter (2002) emphasized the need for nursing interventions to address sleep disturbance and the urgent need for further research to identify the best sleep interventions for caregivers.

### **Sleep Disturbance in Bereaved Family Caregivers**

Recognizing bereavement care as part of palliative care demands that researchers and clinicians consider how caregiver sleep disturbance may influence the bereavement process after the death of a family member. Carter (2005) sought to describe changes in caregiver sleep quality during caregiving and in bereavement. This small

study consisted of in-home interviews with nine adults, who had no previous history of depression or sleep disorders, and who had provided care to family members who had died in the previous six months. Demographic, PSQI, and CES-D data was collected. Three open-ended questions elicited caregiver perspectives on: the caregivers' sleep experience while providing care, the caregivers' sleep experience since the death of the family member, and how sleep influenced daily functioning, quality of life, physical health before and after the death of their family member, and the bereavement processes. Mean scores for PSQI indicated moderate to severe sleep problems and mean scores on CES-D for 7 of 9 participants indicated high risk of clinical depression.

The caregiver narratives revealed that their sleep in the bereavement period was severely disrupted, with descriptions of nightmares which commonly revolved around 're-living the experience' and 'making the right decisions' and of problems waking in the night with difficulty returning to sleep (Carter, 2005). Results raise questions regarding the implications of poor sleep in bereavement as well as during the period of caregiving, and whether sleep disturbance and resulting fatigue negatively impacts the energy required for grief work (Carter, 2005).

### **Sleep Disturbance: Comparisons Across Caregiving Groups**

After reviewing the research from various patient and caregiver populations, it is interesting to consider how the findings from each group relate to the others. Three studies, each designed to illustrate similarities and differences across caregiver groups, were reviewed (Carter & Acton, 2006; Flaskerud, Carter, & Lee, 2000; Teel & Press, 1999). A common thread throughout many of the caregiver populations is the negative correlation between the variables of anxiety, depression, stress and sleep. Flaskerud,

Carter, and Lee (2000) conducted a descriptive study which recruited caregivers (N = 117) through community clinics serving patients with Acquired Immuno-deficiency Syndrome (AIDS: n = 36), Age-Related Dementia (ARD: n = 40), and cancer (CA: n = 41). The purpose of this research was to describe and compare the depressive mood, anxiety, anger, and sleep problems of the female caregivers of patients with varying diagnoses. The CES-D, Symptom Checklist 90-Revised, and PSQI were utilized to measure these variables. Analysis revealed that, when compared to other caregiver groups, cancer caregivers had the least problem falling asleep, but the most trouble with restless sleep and staying asleep. Cancer caregiver sleep problems were significantly related to depressive mood ( $r = 0.46, p < .003$ ), anger ( $r = 0.49, p < .001$ ) and anxiety ( $r = 0.45, p < .003$ ) (Flaskerud et al., 2000). Although all three groups had similar levels of depressive mood, the cancer caregiver group demonstrated the highest levels of anxiety and anger when compared to the others.

A cross-sectional study described personality and coping, and the relationship of these variables with depression and sleep in adult caregivers (N = 51) of cancer patients (Carter & Acton, 2006). Results were then compared to the documented findings in the literature related to caregivers of patients with dementia. It was found that decreased coping, optimism, mastery, and sleep, as well as increased neuroticism predicted 66.4 % of the variance in depression. In turn, decreased coping and mastery, and increased neuroticism and depression, predicted 41 % of the variance in sleep disturbance. These findings, consistent with those of another study of caregivers of community-dwelling Alzheimer's patients (McCurry, Gibbons, Logsdon, & Teri, 2004), demonstrated that there are important predictive negative relationships between sleep disturbance, mood,

and coping that are consistent across caregivers of individuals who have cancer and caregivers of those suffering with dementia.

These findings were also consistent with the results of a previous descriptive study which involved (N = 125) spousal caregivers of patients with Alzheimer's Disease, Parkinson's Disease and cancer, as well as a control group (Teel & Press, 1999). Spousal caregivers of patients with Parkinson's Disease reported caregiving over the longest time periods, spousal caregivers of patients with Alzheimer's Disease reported the largest number of caregiving hours, and cancer caregivers reported the fewest caregiving hours and shortest length of caregiving, yet there was no difference between the three groups based on fatigue and sleep variables (Teel & Press, 1999). Therefore, despite major differences in the functional, cognitive, and behavioral status of the patients between the caregiver groups, all caregiver groups were more fatigued, less energetic and had more sleep difficulties than the control group. These conclusions validate the inclusion of these non-cancer-based research findings not only in this literature review but also in the design of future oncology caregiver research. As palliative care continues to expand its scope of practice beyond oncology patients and families, this information becomes extremely relevant and instructive.

### **Sleep Intervention Research with Cancer Caregivers**

One intervention identified in the literature to manage sleep disturbance, particularly for caregivers of the elderly and demented, is that of respite care. However little is known about either the acceptability of respite care to family caregivers or its effectiveness during the complex period of decline in advanced illness. Given that family caregiver exhaustion has been identified as a major reason for admission of palliative

care patients from community to hospital (Bramwell et al., 1995), further evaluation of the potential merits of respite care are warranted.

Only two studies were located that evaluated respite care as an intervention in palliative home care. In phase one of a two-phase study, Bramwell and colleagues (1995) reviewed existing literature and consulted with expert nurses to create a structured interview schedule to elicit appraisal of the problems, resources, and needs in the palliative phase of family caregiving, as well as to identify factors that contribute to exhaustion and the consequences of this exhaustion for the care recipient. This schedule was then used to interview 37 primary caregivers who used the services of a community hospice.

Telephone or in-home interviews revealed that the majority of caregivers described their sleep time as insufficient; 27% caregivers reported receiving zero to four hours of sleep per night. Of those that received less than four hours of sleep, 90% indicated they would utilize night respite service, compared to 56% of those who slept more than four hours per night. This research also revealed that sleep disturbance is usually underestimated by family caregivers, as the focus of concern for caregivers is the patient, not themselves (Bramwell et al., 1995). The use of recall data in this study and its potential to introduce bias is a limitation of this retrospective study.

Building on Bramwell's (1995) work, Kristjanson and colleagues (2004) conducted a three phase study in Australia which further explored night respite as an intervention strategy. This study involved designing a night respite needs assessment tool, developing a palliative care night respite program, and seeking evaluation of the service from family caregivers. Fifty-three clients received night respite service and 14

caregivers participated in its evaluation. Based on the 29 clients who died at home during the course of the project, 74% of the families required no more than two eight-hour night respite shifts in total.

The 14 caregivers (13 of whom were women) who returned the evaluations indicated that the primary reasons for requiring respite were fatigue or a combination of fatigue with other factors such as: patient restlessness, agitation and anxiety; the need for frequent repositioning, changes due to incontinence, or transfers to the toilet; and the management of complex symptoms. The family caregivers were overwhelmingly supportive of the respite service. The small sample size and non-experimental design are obvious limitations of this study. However the results support existing evidence that night respite offers practical assistance to tired family caregivers, and suggests that family caregivers would actually utilize respite service if it were available to them.

Carter (2006) recently developed a CAregiver Sleep Intervention (CASI) by selecting widely acceptable treatment techniques for primary insomnia, such as stimulus control, relaxation therapy, cognitive therapy and sleep hygiene. These formed a multi-dimensional behavioral intervention approach which could be tailored to meet the goals of individual caregivers in a one-hour session. The feasibility and effectiveness of CASI (vs. body mechanics information) were tested in a small randomized control trial (N = 30 family caregivers: 15 individuals randomized to the intervention and control groups respectively). The effectiveness of the CASI in improving caregiver sleep quality, depressive symptoms, and quality of life was measured utilizing the CES-D, PSQI, the Caregiver Quality of Life Index – Cancer (CQOLC), actigraphy, and sleep logs at baseline, at Week 3 (after the initial intervention), and at Week 5 (following a ‘booster’

CASI). This 'booster', a second one-hour session, sought to review personal sleep and relaxation goal attainment and review information as required from the first session. Carter reported that... "all caregivers showed improvement in sleep quality, depressive symptoms and quality of life over the course of the four-month study" (Carter, 2006, p. 101), however, the sample size limited the extent of data analysis and the generalizability of the findings.

### **Potential Consequences of Sleep Disturbance in Family Caregivers**

Much of the informal caregiver literature addressing caregiver burden, whether physical, emotional or economic, has failed to address sleep disturbance as a factor contributing to this burden. It is reported in the sleep research literature that sleep quality influences daily functioning, quality of life, mental, emotional and physical health (Kryger et al., 2005; Zammit et al., 1999), and bereavement processes (Carter, 2005). Sleep disturbance can affect a person's emotional well-being resulting in irritability, mood changes, anxiety and depression; diminish cognitive capacity which affects attention, memory and problem-solving; slow response time; interfere with psychomotor skills; alter immune functioning; exacerbate existing health problems; and increase the individual's health risks, such as accidental injury (Kryger et al., 2005).

Sleep disturbance in family caregivers may impact their competence, confidence and satisfaction in their caregiving role. Failure to intervene effectively with caregiver sleep disturbance may undermine their ability to care for the dying patient at home (Carter, 2002). Caregiver fatigue necessitating the patient's admission to hospital may be especially disturbing for family caregivers who made a commitment to care for their loved one at home until the time of death.

Based on the home care they provide, family caregivers save the national health care systems billions of dollars each year (Deeken et al., 2003). Premature admission to an institutional setting equates with bed utilization burden and greater costs for the health care system. It has been demonstrated that the cost of overnight respite service for palliative patients in the community is markedly less than the cost of hospice or hospital care for the same time period (Kristjanson et al., 2004). By better understanding the extent of disruption in caregiver's sleep and by promoting restorative sleep for caregivers, health care providers may delay or avoid institutionalization of their patients (McKibbon et al., 2005), resulting in significant savings to the health care system. Moreover, interventions to prevent the deleterious physical and emotional effects of caregiver sleep disturbance may help to prevent family members from themselves becoming our patients.

### **Summary**

This chapter has summarized relevant literature sources related to sleep physiology and pathophysiology, the concept of sleep disturbance, and sleep disturbance in Alzheimer's, Parkinson's and advanced cancer patient and family caregiver populations. Taken as a whole, the literature provides a preliminary understanding of the complexities of sleep disturbance within the advanced cancer patient and the family caregiver population. Research conducted to date with family caregivers of advanced cancer patients must be considered in light of existing limitations. The small, non-random homogenous samples in many studies limit the generalizability of the findings. The majority of the participants were Caucasian women, over the age of 65, highly-educated and living in urban centers. The experience of caregivers who do not reflect these

characteristics is thus not known. A knowledge gap also emerges as to what caregivers suggest would be the most helpful interventions and services to promote sleep while caring for a dying family member. Limited research has been conducted from a qualitative perspective. This foundational research will advance the testing of interventions to promote family caregivers sleep and rest.

## CHAPTER THREE

### CONCEPTUAL / THEORETICAL FRAMEWORK

#### **Introduction**

A theory expresses a unique, unifying idea about a phenomenon (Walker & Avant, 2005), while a conceptual or theoretical framework symbolically represents a set of interrelated concepts providing a theoretical understanding and means of systematic thinking about a particular phenomenon (McEwen & Wills, 2002). Nursing recognizes the need to link nursing research and theory, knowing that research without theory results in discrete pieces of information or data which does not contribute to the accumulated knowledge of the discipline. When a study is placed within an appropriate theoretical context, the theory guides the research process, forms the research questions, aids in the design, analysis and interpretation of the findings (McEwen & Wills, 2002). Therefore, a theory will provide parameters for the research study and assist in weaving the new pieces of information into nursing knowledge.

While both quantitative and qualitative research paradigms link theory or models to research in several ways, the challenge for the novice researcher was to meld the approaches of both perspectives. Quantitative researchers classically explore, test, and redefine pre-existing theory. Therefore the theory identifies salient variables for investigation and guides the research design.

Qualitative research is not concerned with testing theory in the same way that quantitative studies are. Rather, one of the purposes of qualitative research can be inductive theory development. In such instances, the researcher does not begin with pre-existing theory, but rather allows theory to emerge inductively from the findings.

This chapter will describe the theoretical perspectives related to both the qualitative and quantitative aspects of the study. The rationale for the selection of these perspectives versus other potentially relevant frameworks is provided.

### **Theoretical Perspective: Qualitative Portion of the Study**

The purpose of the qualitative portion of this study was to capture the nature of sleep disturbance as experienced and described by family caregivers of advanced cancer patients living at home. The study also sought family caregiver perspectives regarding the factors that contributed to sleep disturbance and the consequences that resulted from sleep disturbance while caregiving. Finally, the study sought to elicit the caregivers' suggestions regarding approaches that might be helpful in addressing the problem of disturbed sleep for these caregivers.

Symbolic interactionism, the theoretical foundation for many qualitative investigations, informs the qualitative portion of this study. This theory is concerned with the experiential aspects of human behavior and people's definition of events (Polit & Beck, 2004) and implies that behavior and meaning emerge from human interactions. As such, it is consistent with the epistemological and ontological underpinnings of qualitative research and provided direction to this study regarding the necessity of collecting descriptive data from participants regarding their own experiences.

### **Theoretical Framework: Quantitative Portion of the Study**

The aims of the quantitative portion of this study was to utilize validated research instruments to collect data that describe sleep parameters such as actual sleep time, sleep latency, time awake after sleep onset and nap time, as well as daytime sleepiness, for family caregivers of advanced cancer patients. The data gathered through the quantitative

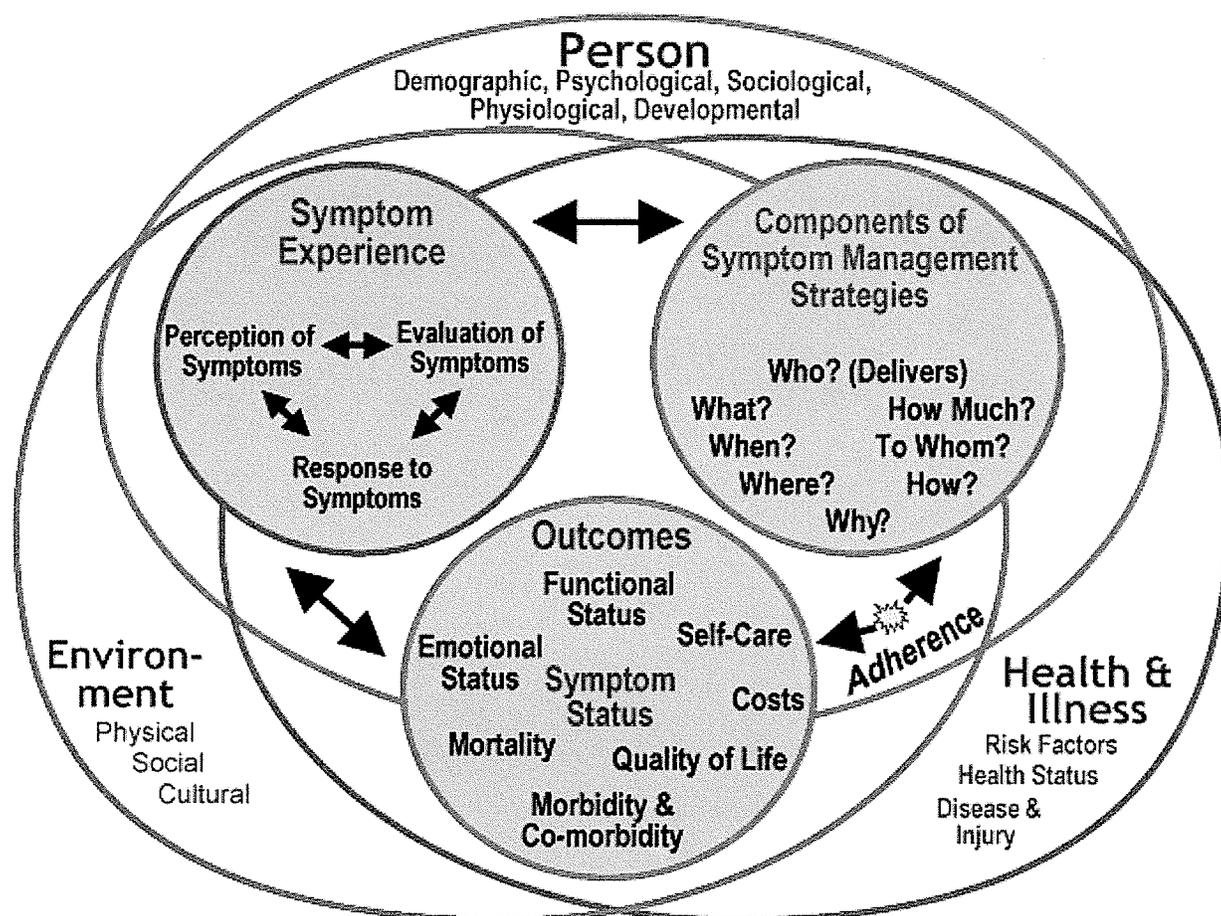
instruments extends and enriches the information gained through the qualitative narratives.

The research- and practice-based Symptom Management Model (SMM) developed by faculty members at the University of San Francisco, School of Nursing (Dodd et al., 2001; Larson et al., 1994) was deemed to provide an excellent theoretical framework to guide research in the area. The faculty's purpose in creating and revising this model was to create a generic symptom management framework that would assist in assessing symptoms and selecting clinical interventions, informing research, bridging an array of symptoms associated with a variety of diseases and conditions, and integrating science from other disciplines.

The model is evidence-based, inductively developed and subsequently revised, based on the authors' clinical practice, research, and scholarly discourse. This nursing model provides a systematic approach for symptom management to improve patient and family outcomes. Dodd and colleagues (2001) refer to this evolving conceptual model as a middle-range theory. It was developed to guide practice, education, and research regardless of: care setting, the disease, or the symptoms; whether care is directed towards individuals, families or groups; whether the focus of care is prevention, cure, or palliation; and whether it is nursing or interdisciplinary in nature.

The three dimensions of symptom experience, symptom management, and symptom outcome are considered within the context of the domains of person, health/illness, and environment. The main concepts referred to as domains and dimensions, rely on concrete sub-concepts to further define and operationalize them. This specificity facilitates the measurement of these concepts [see Figure 3.1, p. 35].

Figure 3.1 Symptom Management Model



### *Application of the Symptom Management Model*

The domains and dimensions with their sub-concepts were instructive in considering how to approach the phenomena of caregiver sleep disturbance in this study.

#### *Symptom Experience*

Under the dimension of symptom experience, the sub-concepts required that qualitative interview questions be developed to explore the caregiver's experience of sleep disturbance, contributing factors, and its meaning in daily life. (e.g. Can you tell me about your sleep while caring for your family member?)

Quantitative data collection including self-report instruments like the Epworth Sleepiness Scale, Pittsburgh Sleep Quality Index, and a sleep log, as well as objective measurement from actigraphy, further describe their sleep disturbance.

### *Symptom Management*

Given the limited understanding of what might be most helpful to promote caregivers rest and sleep in the midst of caregiving, interview questions were drafted to elicit caregiver perspectives regarding potential intervention strategies. (e.g. What would be most helpful to improve the quality and quantity of your sleep? What are important factors to consider in providing these services? Would they utilize these interventions/resources in the midst of providing care to a dying relative, if available?)

### *Symptom Outcome*

The Epworth Sleepiness Scale provided information on the sleep disturbance outcome, daytime sleepiness, while qualitative interview questions explored the consequences of sleep disturbance on the caregiver and the care recipient (e.g. Is it affecting the caregiver's health status? Is it affecting the caregiver's ability to continue to work outside the home?).

“Assumptions are notations that are taken to be true without proof” (McEwen & Wills, 2002, p. 79). The authors state five assumptions in relation to the model: 1) the gold standard in symptom assessment is the person's self-report; 2) the model can be applied to situations where the person is at risk for the development of the symptom, therefore interventions may be preventative; 3) symptoms are experienced by non-verbal patients and the interpretation of symptoms by caregivers will guide intervention; 4) symptom strategies may be directed at individuals, families, groups; and 5) symptom

management is a dynamic process with influences between all dimensions, concepts and domains (Dodd et al., 2001). These assumptions are aligned with those of the researcher and thus framed this family caregiver sleep disturbance study.

### **Limitations of Other Extant Theoretical Perspectives**

#### ***Stress and Coping Theory***

The literature review regarding sleep disturbance in family caregivers of cancer patients revealed that, of the papers which specified a theoretical framework, all utilized stress and coping theory (Bramwell et al., 1995; Carter, 2002; Carter, 2003). The underlying principle purported that caregivers' perception of their experience as well as their appraisal of their abilities to meet the demands, determine the outcomes of this very complex biopsychosocial process (Lazarus & Folkman, 1984; Oberst, Thomas, Gass, & Ward, 1989; Pearlman, Mullan, Semple, & Skaff, 1990; Scott, Oberst, & Dropkin, 1980). While stress and coping are obviously important concepts related to caregiving, the researcher was searching for a pragmatic middle range, practice-based framework that would guide the development of this mixed methods study to produce foundational data for intervention development and testing. The Stress and Coping Framework, based in the behavioral sciences, is considered a grand theory which is complex, broad in scope, and comprised of more abstract, non-specific concepts. This theory has been identified in similar research studies completed in recent years. However, there is limited documentation of how the study findings were integrated back into the theory, which prompted questions concerning its practical application with sleep parameter findings and their application to nursing practice. These considerations supported the use the nursing SMM.

### ***Human Response to Illness Model***

Another important theoretical framework considered in relation to this research was the Human Response to Illness Model (HRI) (Heitkemper & Shaver, 1989; Mitchell, Gallucci, & Fought, 1991). It is a comprehensive, biopsychosocial, nursing model, consistent with the holistic approach of palliative care. The HRI model considers various perspectives to better understand an illness and inform nursing care and research. The four perspectives are: normal physiology (i.e., the normal sleep mechanisms), pathophysiology (i.e., the changes that alter sleep in the individual), behavioral (i.e., how the human response of sleep disturbance is objectively assessed), and experiential (i.e., the lived experience of sleep disturbance). Contextual personal and environmental factors that influence the illness response are also considered important within this model. Despite the scope and depth of this nursing model, it seemed better suited to the actual patient experience of sleep disturbance versus that of the family caregiver, particularly in reference to the pathophysiology perspective. However, working through the components of this model heightened the researcher's understanding of normal sleep physiology and the need to consider personal and environmental factors that contribute to sleep disturbance when collecting data for the study.

### **Summary**

The researcher's theory search and analysis concluded that symbolic interactionism and the Symptom Management Model were good theoretical perspectives to help sensitize the researcher throughout the design, implementation and analysis of this study. In conjunction with *symbolic interactionism*, SMM provides an appropriate perspective from which to develop the qualitative aspect of the project. It was useful in

the development of the semi-structured interview schedule used to explore sleep disturbance experiences with participants. SMM also prompted the types of quantitative data to be collected regarding the phenomena of sleep disturbance in family caregivers providing palliative care. Together, the wisdom of both theoretical perspectives provided a solid foundation for the study.

## CHAPTER FOUR

### METHODOLOGY

#### **Introduction**

The research design delineates the overall plan and strategies employed to develop evidence that is accurate, interpretable and believable (Polit & Beck, 2004). This chapter outlines the research design utilized for this study, providing rationale for the chosen methodology. A synopsis of the sample, setting, recruitment and study procedure, data collection and analysis methods, and ethical considerations will be presented. The researcher will also clearly articulate the processes used to help ensure rigour in qualitative research (Meyrick, 2006), as well as design considerations which contribute to the internal and external validity of quantitative research (Cook & Campbell, 1979).

#### **Study Design**

This descriptive exploratory study utilized both qualitative and quantitative methods of data collection to better understand the concept of family caregiver sleep disturbance. The limited research to date examining sleep disturbance in family caregivers of palliative patients, and the need to more fully understand the phenomenon and its relevant constructs, justifies a qualitative approach (Polit & Beck, 2004). Quantitative data on sleep quality, sleep quantity and daytime sleepiness, collected through the use of validated instruments, in combination with the qualitative data elicited from participants created a rich, strong data set and provided the opportunity for triangulation of the findings (Monti & Tingen, 1999; Streubert Speziale & Carpenter, 2007). It is important to note that, even though this study involved both qualitative and quantitative approaches, the overall nature and design of the study was based on

qualitative methodology. With regards to the quantitative study components, every effort has been made throughout the design, execution, and analysis phases of the study, to maximize the construct, internal, external and statistical conclusion validity as outlined by Cook and Campbell (1979).

### *Sample*

A purposive, convenience sample of 13 adult family caregivers of advanced cancer patients was recruited to participate in this study. All study participants were caring for a family member in the community within the urban area of Winnipeg or the rural area of Interlake in the province of Manitoba, Canada.

In contrast to sampling procedures used in a positivist research paradigm, where the goal is generalizability of the research findings, samples in qualitative studies tend to be smaller and participants are purposefully recruited based on their first-hand experience of the phenomena under study. This intentional selection of participants seeks to maximize the depth and richness of the data to address the research questions (DiCicco-Bloom & Crabtree, 2006).

Placing restrictions on the study sample through inclusion and exclusion criteria helped to delineate the sample and also control for extraneous variables (Pruitt & Privette, 2001). The inclusion criteria for study participants were as follows: i) family caregivers of advanced cancer patients being cared for in the community and registered with the Interlake or Winnipeg Regional Health Authority Palliative Care Programs; ii) 18 years or older; iii) able to read, write and speak English; iv) mentally competent as per the clinical judgment of the palliative care coordinators; and v) willing to share their experience regarding sleep and rest with the research nurse. Those family caregivers who

agreed to take part in the interview portion of the study only (i.e., were not willing to participate in the actigraphy/sleep log portion) were not excluded from the study.

Determination of adequate sample size in qualitative research is based upon saturation, the point at which no new information is forthcoming from further data collection interviews (Streubert Speziale & Carpenter, 2007). In contrast, sample size determination in quantitative research is concerned with involving a large enough number of subjects to be representative of the population and achieve sufficient power for statistical analysis (Pruitt et al., 2001). When combining qualitative and quantitative research in a study, additional considerations are involved in determining sample size. In a study such as this, qualitative interview data was collected to the point of saturation and the data from the standardized quantitative instruments was used for the purpose of providing a fuller description of sleep disturbance in family caregivers, rather than to draw statistical inferences (Sandelowski, 1995). Therefore, power analysis was not used to calculate sample size. Rather, the adequacy of the sample size was judged based on the intended purpose of data collection, the quality of the product, and the extent of the data analysis to be applied (Sandelowski, 1995).

### *Setting*

Participants for this study were recruited through the regional health authorities of Winnipeg and Interlake. In the urban area of Winnipeg, the Winnipeg Regional Health Authority (WRHA) Palliative Care Program (PCP) coordinates the care of patients who wish to remain in their own homes for as long as possible. Each patient is assigned a Palliative Care Coordinator to oversee and coordinate services such as nursing visits, home care attendants, and home-help. From April 1, 2007 to March 31, 2007, 1,343

patients were registered on the program (Email communication, L. Embleton, April 20, 2007) and 86% of these patients had a cancer diagnosis. Over the past few years, an increasing number of these cancer patients have been cared for at home until the time of death. In this past year, 25% of the patients on the program died in the home setting.

In the Interlake Regional Health Authority (IRHA) similar services are coordinated for the patients living at home throughout the palliative phase of their cancer illness. In the previous year, 123 new patients were registered with the Interlake Palliative Care Program and of these, 80% had a cancer diagnosis. In this rural region, approximately 20% of the patients died in the home setting (Email communication, S. Pyziak, June 26, 2007).

### *Procedure*

Prior to data collection, approval of the University of Manitoba Education and Nursing Research Ethics Board was obtained on January 8, 2007 [see Appendix A, p. 174] and WRHA and IRHA site access was granted on January 10 and 19th, 2007 respectively [see Appendix B & C, p. 175 & p. 176]. The researcher proceeded by organizing meetings with the regional administrative staff and the palliative care coordinators, who were responsible for the initial contact with potential study participants. These meetings took place with the IRHA staff on January 23, 2007 and the WRHA staff February 15, 2007. An overview of the study was provided outlining the coordinator's role in the recruitment procedure, the inclusion criteria required for eligibility, and the initial contact script for their use [see Appendix D, p. 177].

Subsequently, the coordinators identified family caregivers of patients registered with or newly referred to each regional palliative care program who met the study's

inclusion criteria. The coordinators explored the family members' interest in learning more about the study, utilizing the brief contact script provided by the researcher. This scripted introduction of the study to potential participants ensured consistency of approach across staff members and regions. With the family members' permission, the palliative care coordinator shared their names and phone numbers with the researcher, via phone or email.

The researcher contacted potential participants by telephone within 24 hours to provide further information regarding the study and determine their interest in participating. If the family caregiver agreed to proceed, the researcher arranged a mutually agreed upon date, time and meeting place. Despite the option to meet in an alternate location, all participants except one, chose to meet with the researcher in the home where the patient resided. One participant was interviewed in her own home.

Prior to data collection, the Information and Consent Forms were reviewed with the family member and written consent obtained [see Appendix E, p. 178]. Participants were also asked at this time, if they wished to receive a summary report of the research study. If they indicated 'yes' on the Information and Consent Form, they were asked to provide their mailing address on the same form. Then utilizing a structured interview format with participants, the research nurse filled in the Demographic Data Collection Form [see Appendix F, p. 183], the Epworth Sleepiness Scale [see Appendix G, p. 184] and the Pittsburgh Sleep Quality Index [see Appendix H, p. 185], and recorded their responses in pen. This format worked well to ensure participant understanding of the questions and optimize completeness of the data set. These techniques of engaging the participants in the process, providing in-person explanations and assistance with the

instruments optimized the participation in this vulnerable population (Pruitt & Privitte, 2001).

The researcher then proceeded to explore the caregiver's experience of rest and sleep, utilizing the Semi-Structured Interview Guide [see Appendix I, p. 189]. The complete interview, including the completion of the research instruments, ranged from 50- 90 minutes in length. The length of the visit was determined by how much the caregiver wished to share and in some cases, by the number and length of interruptions that occurred during data collection due to caregiving demands that arose. These interruptions occurred in eight of the thirteen interviews.

In order to objectively evaluate family member sleep patterns (Carter, 2003), at the end of the interview, participants were asked if they would be willing to wear an actigraph [see Instruments, p. 47] and record a brief sleep log [see Appendix J, p. 191] over the following 72-hour period. If the caregiver was willing to participate in this facet of data collection, time was taken to instruct the participant on the use of the actigraph, review the Instructions for Use of Actiwatch® [see Appendix K, p. 198] and schedule a second visit to pick up the sleep log within 3-5 days. This portion of the visit usually took an additional 5 - 10 minutes. The researcher attempted to contact the participant by telephone the day following the first visit to ascertain whether there were any questions related to the actigraph or sleep log. The researcher also contacted the participant prior to the second visit to confirm pick-up of the actigraph and the sleep log. The second visit was never longer than 15 minutes. The research nurse's phone number was left with each participant if questions should arise or their situation change. At the conclusion of the first and second visits, the participants were thanked for their participation, and at the

second visit, clarified that no further contact with the researcher would occur until the summary report was mailed later in 2007, unless the participant initiated further contact.

### *Data Collection/Instruments*

#### *Qualitative Interview*

In-depth interviews can provide rich information about the experience and perspectives of research participants (DiCicco-Bloom & Crabtree, 2006). The researcher conducted face-to-face interviews with each family caregiver, capturing narrative accounts of his/her experience. The interviews were planned for the location that the participant chose as most convenient and comfortable. In a study such as this, it is very important that the participants feel safe and comfortable, in order to share freely with the researcher, while responding to questions (DiCicco-Bloom & Crabtree, 2006). All interviews were conducted in the community setting in the patient's or family member's home; it soon became preferable that the patient, family or other caregivers not be in the same room during the interview. All caregivers indicated that they felt more comfortable answering the questions when they were alone with the researcher. To ensure optimal data generation, effective interview skills were employed. Establishing trust and rapport, ensuring privacy, finding a quiet environment, using non-judgmental responses as well as appropriate humour, were critical elements woven throughout the caregiver interviews.

A semi-structured interview guide [see Appendix I, p. 189] of open-ended questions derived from the literature and informed by the study's theoretical framework was used to guide, but not limit, the interview process. Active listening techniques and probes were utilized to encourage participants to expand on their thoughts and experiences as well as to clarify information shared. With the semi-structured format, the

focus was sleep disturbance, but the format also allowed the flexibility for additional scope and depth in the family caregivers' responses. The semi-structured interview guide remained fluid, allowing for refinement of the questions as the study progressed and data was analyzed, to optimize the richness of the data collected. Changes were not deemed necessary to the interview guide as the study progressed, however the researcher reviewed the audio-tapes and the typed transcripts to further refine interview techniques as the study proceeded. Member checking, which is a process of checking back with participants to see if they recognize the findings (Streubert Speziale & Carpenter, 2007), was utilized from one interview to the next. It is acknowledged that the researcher employed an altered form of member checking. Rather than the researcher returning to the original participant for verification of the data collected, the researcher explored whether the thoughts and experiences of one participant resonated with the thoughts and experiences of the following participants (e.g., Some family members have described their sleep as fragmented, does this describe your experience?). With the caregivers' permission, interviews were audio-recorded and transcribed verbatim by an experienced transcriptionist to preserve their accuracy.

### ***Quantitative Instruments***

In order to describe the characteristics of the sample, and collect information about caregivers' daytime sleepiness and dysfunction, sleep quality, sleep latency, total sleep time, sleep efficiency, and use of sleep medication, the following research instruments were utilized employing a structured interview format:

***Demographic Data Collection Form.*** [see Appendix F, p. 183] This data collection form was created by the researcher, based on the literature review, to capture

details about the study participants and their care recipients. This information enabled the researcher to describe the characteristics of the sample and aided in the interpretation of the data. Patient demographic data was collected from the study participants. It was important to understand the health status of the patients they were caring for to better understand their situation and the caregiving demands. This patient and participant information was only available via self-report from the participants as the researcher did not have permission to interview the patients or to access personal health information records.

*Epworth Sleepiness Scale (ESS)* (Johns, 1991) [see Appendix G, p. 184]. This simple eight-item questionnaire has been widely utilized in research and practice to capture caregiver subjective assessments of their daytime sleepiness in recent times. When the eight item ESS scores representing different situational sleep propensities are added together, they yield a total ESS score between 0 - 24, which is a measure of the subjects' average sleep propensity in those eight situations. 'Normal' adults who do not have evidence of a chronic sleep disorder (including snoring) have a mean ESS score of 4.6 (confidence intervals 3.9 - 5.3) with a standard deviation of 2.8 and a range from 0 - 10 (Johns, 1991; Johns & Hocking, 1997). Therefore, scores  $\geq 11$  would indicate excessive daytime sleepiness. The ESS has a high level of internal consistency assessed by Cronbach's statistic ( $\alpha = 0.88$ ), proven test-retest reliability, and factor analysis confirms its validity as a tool for measuring daytime sleepiness (Johns, 1992). Permission to use the ESS was obtained from Dr. Johns, along with an up-to-date version and additional information regarding its use (Dr. M. Johns, email communication, October 2, 2006).

***Pittsburgh Sleep Quality Index (PSQI)***. (Buysse, Reynolds III, Monk, Berman, & Kupfer, 1989) [see Appendix H, p. 185]. This index has 19 self-rated questions that require the participant to reflect upon the previous month and describe his or her sleep experience and daytime energy levels. The items are used to calculate seven sleep component scores, each ranging from 0 - 3 with the desired range 0 - 1. Sleep component scores can be summed to produce a global or total sleep score, ranging from 0 - 21. Global scores  $\geq 5$  indicate moderate sleep problems in at least three sleep components or severe sleep problems in two areas (Buysse et al., 1989). This tool has proven internal consistency with Cronbach's alpha ranging from of .83 to .89, test-retest reliability in healthy adults, and validity when compared to polysomnography in healthy adults (Buysse et al., 1989; Carpenter & Andrykowski, 1998; Carter & Chang, 2000). Carter (2000, 2003) found the PSQI to be an effective instrument to use in family caregiver research. Permission was received from Dr. Buysse to utilize the PSQI in this study, including guidelines for implementation and the scoring algorithm (Email communication, Dr. J. D. Buysse, October 5, 2006).

***Actigraphy***. The actigraph, a wrist-watch sized accelerometer worn on the caregiver's non-dominant wrist, senses movement and provides an objective measurement of rest and activity patterns around the clock. It is a sensitive, non-invasive, easily applied, and widely-used instrument to assess people's sleep in their own environment (Lichstein et al., 2006). Actigraphy recordings and polysomnography recordings of whole night sleep measures (sleep duration, sleep latency, and wake after sleep onset) are highly correlated ( $r = 0.89$  to  $0.98$  in normal sleep and  $r = 0.78$  to  $0.88$  in severely disturbed sleep) (Ancoli-Israel et al., 2003; Jean-Louis, Kripke, Cole, & Langer,

2001). For the purposes of this study, four actigraph devices (Actiwatch-64®), products of the Mini Mitter Company, Inc. with the corresponding computer software (Actiware®) for downloading and analyzing the data, were made available through Dr. Diana McMillan, University of Manitoba, Faculty of Nursing. The Actiwatch-64® contains 64 kilobytes of on-board memory and an event marker button which allows participants to mark specific events such as when they turn the light off at night, when they awaken in the morning, and when they remove the watch to shower or bath. The logging capacity of the Actiwatch-64 is determined by its memory capacity and the epoch length [the frequency of measurement and recording] set by the researcher.

Prior to the first visit to each participant, the research nurse activated an Actiwatch® utilizing the Actiware® software, checked the watch to ensure adequate battery life, and established the reading intervals (epoch length) at .25 seconds. This setting allowed data to be recorded for up to 11 days, which in turn allowed sufficient time for the first and second visit and return to the university. If the caregiver was willing to participate in the actigraphy portion of the study, the research nurse showed the participant how to wear the instrument, reviewed the instructions for the 72-hour period while wearing the watch, and recorded the start and stop dates/times for actigraphy data collection on the participant's sleep log. Prior to the eleventh day, the researcher retrieved the actigraph, downloaded and stored the data, using the participant's anonymous code as the computer file name. Actiware® allowed the researcher to identify the specific 72-hour period of data for analysis.

***Sleep Log.*** Each caregiver was asked to record a brief sleep log (e.g. bed time, wake time, timing of sleep interruptions and naps) for 72 hours while wearing the Actiwatch-64® [see Appendix J, p. 191]. The caregiver also recorded on the sleep log when and why the Actiwatch-64® was removed and reapplied. These logs assisted with the analysis of the actigraphy data. The sleep log utilized in this study was developed and used by Carter (2006) in studies examining family caregiver sleep in the United States. A copy of this log and permission was obtained from the author, Dr. Carter. Previous research suggested that actigraphy and completion of the sleep log is not unduly burdensome for family caregivers of cancer patients (Carter, 2003; Carter, 2006). Participants re-affirmed this throughout the current study.

### ***Reflexive Journal***

The researcher kept a journal throughout the design, data collection and analysis phases of this study. This was an informal ongoing recording of details, assumptions, feelings, and observations throughout the process, intended to strengthen the data collection and analysis process. Journaling is important for tracking information that may influence or bias data collection, as well as analysis, as it allows the researcher to bracket, or set aside her own perspective, ensuring that it is the participant perspective that is presented (Streubert Speziale & Carpenter, 2007).

## ***Ethical Considerations***

### ***Ethical Approval***

Prior to the commencement of data collection, University of Manitoba Research Ethics Board approval and site access were secured. Regional palliative care program staff have an ongoing commitment to innovative and evidence-based service delivery to

the patients and families registered with their programs. Regional staff were therefore very receptive to participating in this research study and keenly supported the process.

### ***Informed and Written Consent***

Participation in the study was strictly voluntary and subjects were able to withdraw at any time. Prior to data collection, the Information and Consent Form [see Appendix E, p. 178] was reviewed with the participants. The process of obtaining written informed consent provides an important opportunity for the nurse to communicate the details of the study as well as potential risks and benefits associated with participation (Casarett & Karlawish, 2000). Minimal risk or harm to the subjects was anticipated. As an experienced palliative care nurse, the investigator was well aware that the family caregivers may become emotional during the interview process; she was also aware that discussion of emotional topics with caregivers may serve to validate their feelings rather than cause negative effects (Hudson et al., 2005). No incentives or honoraria were offered to participants for their involvement in this project.

### ***Sensitivity Issues***

Palliative care patients and their families are considered a vulnerable population (Casarett & Karlawish, 2000; Hawryluk, 2004), therefore care was taken throughout the design and implementation of the study to remain sensitive to the time, intensity, burden, and issues inherent in palliative care. Because sensitivity to the target population is critical, many factors were considered to minimize burden and remain responsive to the needs of the participants (Dean & McClement, 2002). If the research nurse became aware that the caregiver had specific needs which required immediate attention, the Semi-Structure Interview Guide was set aside and the researcher allowed the family member to

focus on the issues at hand. For example, five of the thirteen study participants became emotional and teary when sharing experiences. Time was allowed to acknowledge their feelings, allow them to regain their composure and assess if they wished to continue. The researcher gave the participants the option of taking a break or terminating the interview. In each of case, the participants expressed an interest in completing the interview.

During the interviews, it was important for the researcher to remain sensitive to the participants' needs for follow-up by the Palliative Care Coordinator after the research interview. The purpose of this follow-up may include assessment and planning for additional emotional support, information, services or equipment. The decision regarding the need for follow-up was made jointly with the caregiver. It was also determined whether the researcher would contact the Palliative Care Coordinator or the participant would follow-up independently. In two of the thirteen situations, the researcher was given permission by the participant to contact the coordinator on their behalf. It was also planned, that if the research nurse should become aware of serious sleep problems during the interview or data analysis, she would ask the participant to report these concerns to their Palliative Care Coordinator or family physician for follow-up. This was not deemed necessary in the course of this study. It is important to note that the researcher was not employed by either the WRHA or the IRHA at the time of this study; caregivers were assured that information that they shared would not be communicated to or affect the care that they and the patient were receiving, thus negating issues of dual agency for the researcher (Edwards & Chalmers, 2002).

### *Confidentiality and Anonymity*

To maintain the anonymity of the participants, each person participating in the study was assigned a unique code number. That code number appeared on all data collected from the individual, not his or her name. The researcher kept a master list linking the participants' names and their code numbers in a locked drawer in her home office, separate from consent forms and raw data.

The audio-taped interviews were transcribed by an experienced transcriptionist; all names and identifying information were replaced by pseudonyms. The researcher held in confidence all information shared by participants. In two cases, permission was gained from the participant for the researcher to contact the palliative care coordinator to convey information which was helpful to the planning of care for the patient and family caregiver. The data presented does not contain any names or other identifying information about participants, and is presented in aggregate form, with the exception of anonymized quotes to exemplify themes in the qualitative analysis. All data and research materials are stored in a locked filing cabinet in the researcher's office. The interview transcriptions are stored on the researcher's computer which only she can access. Actigraphy data was anonymized, downloaded, and analyzed using the computer/Actiware software which is kept in the locked office of Dr Diana McMillan, Faculty of Nursing (Internal Member of Thesis Committee); the researcher and Dr McMillan have exclusive access to the data using a specific computer access code. Study data will be kept secure for a period of seven years after which time it will be destroyed and treated as confidential waste.

## **Data Analysis**

### ***Qualitative Data***

#### ***Analysis Procedure***

The challenge for the qualitative researcher is to develop an interpretation of the lengthy narrative accounts that creates meaning, accurately reflects each individual's experience, and applies equally well across the data set (Ayres, Kavanaugh, & Knafl, 2003). The qualitative data analysis presented the most daunting challenge to the novice researcher, given the quantity of data, coupled with the commitment to honor the participants by accurately and meaningfully conveying the findings. It was reassuring to have these feelings verified by numerous well-known qualitative researchers (Loiselle & McGrath, 2004; Sandelowski, 1995; Thorne, 2000).

In reality, this iterative process of qualitative data analysis started at the initiation of data collection, as data collection and analysis occur concurrently in qualitative research. From the first family caregiver visit forward, the researcher reflected on the interviews and spent time listening to the audio-recordings of the participant interviews. Themes emerging from the interviews were discussed throughout the data collection time period with the researcher's supervisor and used to create a template to guide future coding (DiCicco-Bloom & Crabtree, 2006). The researcher informally validated the findings from one interview with participants in the next interview, thereby engaging in a form of member checking that helped to ensure the rigour of the analytic process (Loiselle & Profetto-McGrath, 2004).

The researcher also kept a reflexive journal throughout the study, jotting details, observations, and thoughts to strengthen the accuracy of the data collection and analysis

process (Maxwell, 2005). This journaling helped to track biases, assumptions and other contextual issues related to the interviews that may have inadvertently influenced the caregivers' narratives as well as the coding process. This journaling process continued throughout the period of analysis and interpretation of the findings.

Once the audio-recordings were transcribed verbatim by an experienced transcriptionist, they were stored on the researcher's computer hard drive, and one hard copy of each interview transcription was printed. As an additional step to ensure rigour, the thesis supervisor coded three randomly chosen transcripts. Therefore, a second copy of three transcripts was shared with Dr. McClement for analysis purposes.

Throughout the interviews and the analysis of the transcripts, content analysis and constant comparison techniques were used (Streubert Speziale & Carpenter, 2007). Content analysis refers to the process of organizing and interpreting narratives and qualitative information into emerging themes (Polit & Beck, 2004). This was a satisfying process as it began to reduce large amounts of data into organized segments (Marvasti, 2004). During the process of identifying these themes, constant comparison involved considering pieces of data and their relationship with other pieces of data (e.g. What is this? What is going on? What does this stand for? What is similar or different about it?) (Loiselle & Profetto-McGrath, 2004). Comparative analysis also encompasses the interplay between the data and the researcher throughout the process (Strauss & Corbin, 1998), and the researcher would also add, between the researcher and supervisor.

The transcripts, reflexive journal notations, and the sleep logs were analyzed utilizing the above approaches. To lend further structure to a rather ambiguous task, the

following steps were taken to comprehend and synthesize the data (Ayres, Kavanaugh, & Knafl, 2003; Loiselle & Profetto-McGrath, 2004; Marvasti, 2004; Sandelowski, 1995):

1. First, the researcher repeatedly read through the complete data set to gain a general understanding, and begin to comprehend the essential features.
2. Secondly, the researcher read through each transcript line by line, noting open codes in the margins. Open coding, is the first stage of constant comparative analysis, as it begins to capture the essence of the data (Polit & Beck, 2004). While performing this initial categorization of data, the researcher began to sense the lived experience of sleep disturbance in family caregivers.
3. In the third step, the researcher created a list of all open codes noted for each transcript. This produced thirteen extensive and varied lists.
4. The fourth step of the process was, to consider the open code list for each transcript individually, and begin to cluster the open codes into themes. As a result, a list of themes emerged from each transcript.
5. With the 13 lists of clusters or themes at hand, the researcher searched for common themes across transcripts.
6. Throughout this process, the researcher wrote and further defined each cluster, i.e. determining the meaning of a particular theme, and thus, creating definitions of each theme.

Throughout these steps, coding schemes, emerging clusters and themes were compared between the researcher and supervisor. Discussion illuminated and crystallized the

findings and consensus was attained. Therefore, memo-writing, reading and rereading, coding, creating diagrams and discussion were techniques utilized by the researcher which supported the principles of comparative analysis (Boeije, 2002).

### ***Measures to Enhance Methodological Rigour***

To ensure that qualitative research provides trustworthy evidence to inform today's health care practice, research studies must incorporate necessary design mechanisms to maximize rigour. Similar to reliability and validity in quantitative research, goodness or rigour is essential in qualitative research. Guba and Lincoln (1994) identified four operational techniques which support rigour in qualitative work: credibility, dependability, confirmability, and transferability.

***Credibility.*** Credibility, considered to be the primary validity criterion, refers to the degree of confidence regarding the truth of the data and its interpretation (Loiselle & Profetto-McGrath, 2004). The research design must include activities which increase the likelihood of credible findings. To establish credibility, the researcher must have prolonged engagement with the subject matter (Streubert Speziale & Carpenter, 2007). The researcher in this study was immersed in the process of data collection and analysis over a five month time period. In-depth understanding of the culture and views of the group under study, as well as the ability to build trust and rapport with the participants, increase the chance that useful, accurate and rich information will be obtained (Polit & Beck, 2004). The investigator's experience and credibility in the palliative care community contributed to her engagement in the subject matter, the credibility of the manner in which the research was conducted, as well as the product. Polit and Beck (2004) refer to this as researcher credibility.

Koch (2006) purports that “self-awareness of the researcher is essential” (p. 92) to enhance credibility. Documentation in a field journal, listing assumptions prior to data collection and analysis, and self-reflection were employed to increase self-awareness throughout the study. Consulting with participants to clarify and ensure accuracy of the data collected and interpretation of the findings is also important (Kock, 2006). The researcher utilized brief conversations during the second visit to participants [for the purpose of picking up the Actiwatch and sleep log], as informal member checks to clarify information as required. Similar to member checking, the researcher increased credibility by checking data from one participant to the next (e.g. “Other participants have reported that it feels like they are sleeping with one eye and ear open - does that describe your experience?”)

Another criterion to increase credibility is triangulation (Streubert Speziale & Carpenter, 2007). Triangulation is important as it creates the frame of mind for the researcher to critically regard her data, analysis and interpretations. This is similar to a ‘self-checking’ function which increases the researcher’s confidence in the findings, thus enabling the dissemination of the findings to a broader audience (Williamson, 2005). Data and method triangulation were design features of this study aimed to produce a more complete picture of the phenomena of family caregiver sleep disturbance and to increase the dependability of the findings. As outlined earlier, multiple data sources utilizing qualitative and quantitative approaches were utilized including interview narratives, validated research instruments, actigraphy and sleep logs.

Investigator triangulation was also employed to enhance dependability as the research nurse involved members of her thesis committee in the analysis, interpretation,

and discussion of the data set. This collaboration brought the richness of various perspectives, but also reduced the possibility of biased interpretation, similar to inter-rater reliability in quantitative studies (Loiselle & Profetto-McGrath, 2004).

***Dependability.*** Dependability is another component that must be addressed to ensure trustworthiness of qualitative research findings. It concerns the stability of the qualitative data over time and over various conditions (Loisell & Profetto-McGrath, 2004). One approach to ensure dependability is an inquiry audit by an external reviewer. Other approaches to enhance dependability are the triangulation techniques already outlined. In this study, data triangulation from the various sources and investigator triangulation served to enhance dependability. The thesis chair, who has recognized expertise in the field of palliative care and qualitative research, independently coded three of the thirteen transcripts, supervised the researcher in the coding of all the transcripts and collaborated on the categories and themes that emerged.

***Confirmability.*** Confirmability is concerned with the “objectivity and neutrality of the data” (Polit & Beck, 2004, p. 437). In other words, the research findings should reflect the participants’ experiences, not those of the researcher. According to Koch (2006), confirmability follows credibility and dependability. It requires that the researcher demonstrate the pathway or audit trail to the findings – a technique of rigour (Meyrick, 2006). Sandelowski (1986) states that, findings are auditable when another researcher can follow the decision-making trail used by the researcher to see if he or she would arrive at similar conclusions. Using a systematic approach, clearly articulating the research design, procedures, and analysis, as well as meticulous documentation throughout the process, are believed to increase the transparency, thus, audibility, of

this study (Thorne, 2000). The researcher has made every effort to illustrate the evidence objectively, as well as the thought process leading to the conclusions of this research thesis.

***Transferability.*** Transferability implies that the research findings have meaning in similar situations (Streubert Speziale & Carpenter, 2007); it resembles generalizability in quantitative studies. In qualitative research, the researcher must provide enough information regarding the sample, setting, and context as well as a rich representation of the descriptive data, to allow someone else to judge whether the findings may apply to another setting or group (Koch, 2006; Meyrick, 2006). Another term for transferability is fittingness. By providing a thorough synopsis of this research study, other potential users will be able to determine if these findings apply to other situations. Later, in the discussion of the findings [see p. 114], the results of this study will be compared to similar studies conducted by Carter (2002, 2003) which will broaden the concept of transferability in relation to this study.

***Summary.*** The four criteria utilized to judge the rigour of qualitative research have been considered in the design, implementation and analysis phases of this study. Credibility, dependability, confirmability, and transferability help to define the attention rendered to a qualitative research study such as this one, as well as the potential to mirror the process (Meyrick, 2006).

### ***Quantitative Data***

During the course of data collection, the researcher created an outline of the study variables, measurements used to capture the information, the level of data, and the statistical tests deemed appropriate for analysis. This plan was reviewed with Dr.

McMillan, thesis committee member specializing in quantitative methodology, and Mary Cheang, statistician for the Manitoba Nursing Research Institute. The plan was further refined and utilized to guide the analysis of the quantitative findings. This section outlines the steps of the quantitative analysis that was carried out.

At the end of the data collection period, the researcher analyzed the stored actigraphy data using the Actiware® computer software program belonging to Dr. Diana McMillan. The actigraphy data for each participant was analyzed in conjunction with the participants' recorded sleep log to increase the accuracy and understanding of the analysis (Stepanski, 2005). Dr. McMillan, a nursing expert in sleep research supervised the analysis; the Instruction Manual produced by the Mini Mitter Company, Inc. (2003) for the Actiwatch-64® was also a helpful resource to both the researcher and supervisor throughout the analysis process.

The following variables were calculated from the actigraphy, for each participant: sleep latency, time in bed, sleep efficiency index, fragmentation index, wake time, and number and length of daytime naps. A hard copy of the actigraphy results for each participant was printed utilizing their anonymous code number. This allowed the researcher to conduct further statistical analysis of the actigraphy findings.

Throughout the study, the ESS and PSQI scores were calculated according to the authors' guidelines. Spread sheets were created to record the values for the study variables obtained via the demographic form, actigraphy, ESS and PSQI instruments. At the end of the data collection period, the data was entered into SPSS for Windows statistical software program for data analysis. The staff at the Manitoba Nursing Research

Institute, including statistical consultant, Mary Cheang, assisted throughout the process of data coding, analysis and interpretation.

Descriptive statistics such as percentages, central tendencies (e.g. means and medians), and variability (e.g. range and standard deviation) were used to summarize and communicate the demographic data, providing a profile of the study participants and care-recipients. These same descriptive statistics as well as bivariate descriptive statistics (e.g. Spearman's rho correlations, scatter plots, histograms and contingency tables) were used to synthesize, compare, interpret, and communicate the ESS, PSQI, and actigraphy data.

Correlations in the data were calculated using Spearman's rank-order correlation, also referred to as Spearman's rho ( $r_s$ ) for nominal and ordinal data and product-moment correlation coefficient, known as Pearson's  $r$  ( $r$ ) for interval and ratio data (Loiselle & Profetto-McGrath, 2004). The researcher explored a number of correlations, including the correlation between the PSQI self report scores for sleep duration as compared to the actigraphy data for this variable, the correlation between the care-recipient's level of functioning (i.e. level of care) and the caregiver's actual sleep time, and the relationship between the care-recipient's days lived after the interview and the caregiver's sleep efficiency. Statistical analysis was limited due to the small sample size of 13.

#### *Analysis of Triangulated Qualitative-Quantitative Data*

Once the quantitative data was analyzed statistically using SPSS, and the narrative data was analyzed using qualitative techniques, the researcher interpreted the overall patterns, considering both components simultaneously. In this way the researcher was challenged to understand how the findings from each methodology related to each other,

noting similarities and differences. This approach of integrating and interpreting the data from both sources, after the fact, is recommended by Polit and Beck (2004).

Triangulation of the study findings will be woven throughout the discussion of the findings in Chapter Six [see p. 114].

### **Summary**

This chapter has outlined the research design utilized to explore the phenomenon of sleep disturbance in family caregivers of advanced cancer patients. The methodology, sample, setting, procedure, data collection instruments, and data analysis were presented. Consideration of ethical approval, confidentiality and anonymity, as well as measures to enhance rigour, has been addressed. Chapter Five presents the findings which emerged in this research study.

## CHAPTER FIVE

### FINDINGS OF THE STUDY

#### **Introduction**

The overarching purpose of this study was to explore and describe the concept of sleep disturbance as experienced by family caregivers of advanced cancer patients living in the community, with the aim of identifying potential intervention strategies to ameliorate these disturbances. This chapter provides a descriptive profile of the study participants and the patients they were caring for based on the demographic data collected. Subsequently, the findings which emerged from the caregiver interview data and the quantitative research instrument data will be presented.

#### **Description of the Study Participants**

Sixteen family caregivers were referred to the study and of these, 13 participated. Two family caregivers became ineligible to participate as their family member died prior to the scheduled interview, and one family caregiver declined indicating she was “too busy.” Of the 13 family caregivers who participated in the study, only one chose not to participate in the actigraphy component, citing that “the interview was a sufficient commitment at this time.”

#### ***Description of the Caregiver Participants***

Of the thirteen participants recruited to this study, six lived in the Interlake health region and seven lived in the Winnipeg region. The ages of the family caregivers interviewed ranged from 41 to 73 years, with a mean age of 58.5 years (Standard Deviation (SD) = 9.7 years). All participants were Caucasian, ten (76.9%) of whom were female and three (23.1%) were male. Seven of the participants (53.8%) were spouses of

the patient, while four (30.8%) were either a son or a daughter, and two (15.4%) were siblings. It is interesting to note that eight of the thirteen participants were employed in varying degrees. Five of the eight had altered their employment status due to their caregiving role by decreasing their hours of work, utilizing sick-time or arranging a leave of absence. Not one of the thirteen had applied for Compassionate Leave Benefits. All the participants described their health as good to very good, even though four of the thirteen noted that they had a history of at least one chronic illness. Refer to Table 5.1 for further details related to the family caregiver participants.

**Table 5.1 Demographic Profile of the Caregiver Participants**

<b>Characteristics</b>	<b>Total Sample (N=13)</b>
<b>Age:</b>	
40-49 years	2 (15.4%)
50-59 years	6 (46.2%)
60-69 years	3 (23.1%)
70-79 years	2 (15.4%)
<b>Gender:</b>	
Female	10 (76.9%)
Male	3 (23.1%)
<b>Race:</b>	
Caucasian	13 (100%)
<b>Educational level in years:</b>	
6-11 years	2 (15.4%)
12-15 years	9 (69.9%)
>15 years	2 (15.4%)
<b>Employment status:</b>	
Retired	5 (38.5%)
Full-time	1 ( 7.7%)
Full-time, currently part-time	2 (15.4%)
Full-time, currently on sick leave	1 ( 7.7%)
Full-time, currently on disability	1 ( 7.7%)
Part-time	2 (15.4%)
Part-time, currently on leave	1 ( 7.7%)

<b>Relationship to patient:</b>	
Spouse	7 (53.8%)
Child	4 (30.8%)
Sibling	2 (15.4%)
<b>Length of caregiving in months:</b>	
0-6 months	4 (30.8%)
7-12 months	5 (38.5%)
13-18 months	0 ( 0.0%)
19-24 months	2 (15.4%)
25-30 months	1 ( 7.7%)
31-36 months	1 ( 7.7%)
<b>Caregiver's primary residence:</b>	
Yes	9 (69.2%)
No	4 (30.8%)
<b>If no, distance from own home:</b>	
< 1 kilometre	2 (15.4%)
2-35 kilometres	1 ( 7.7%)
36-70 kilometre	1 ( 7.7%)

The family members had varying perspectives when asked how long they had been caregiving. Many referred back to the original date of the patient's cancer diagnosis, noting specific events and dates across the cancer illness trajectory, including surgeries, hospitalizations, disease recurrences, disease metastases, and the discontinuation of chemotherapy. It was often difficult for them to identify when their role of caregiving began as they indicated that it had merely changed over time. The length of caregiving identified by these family members ranged from 1.5 to 34 months, with an mean length of 12 months caregiving (Median (Md) = 13.3).

### *Description of the Patients*

In a study of this nature, it is important to consider the characteristics of the patients or care-recipients in the home. This information helps to illuminate the demands of caregiving. The mean age of patients was 77.3 years (SD 10.8 years). Seven were female (53.8%) and six were male (46.2%). The most common cancer diagnoses in this patient population were lung (n = 4; 30.8%), lymphoma (n = 3; 23.1%), and bladder (n = 2; 15.4%). The Palliative Performance Scale is used to communicate the functional ability of the patient, with 100% representing full function and 0% representing death. Patients' scores in this study ranged from 10-50% with a mean score of 39.2%. Please refer to Table 5.2, Demographic Profile of the Patients, for further details [p. 69].

**Table 5.2 Demographic Profile of the Patients**

<b>Characteristic</b>	<b>Total Sample (N=13)</b>
<b>Age:</b>	
60-69 years	4 (30.8%)
70-79 years	3 (23.1%)
80-89 years	5 (38.5%)
90-99 years	1 ( 7.7%)
<b>Gender:</b>	
Female	7 (53.8%)
Male	6 (46.2%)
<b>Primary Diagnosis:</b>	
Lung	4 (30.%)
Lymphoma	3 (23.1%)
Bladder	2 (15.4 %)
Pancreas	1 ( 7.7%)
Colon	1 ( 7.7%)
Gastric	1 ( 7.7%)
Non-cancer diagnosis	1 ( 7.7%)
<b>Palliative Performance Scale:</b>	
1-10%	2 (15.4%)
11-20%	0 (0.0%)
21-30%	0 (0.0%)
31-40%	5 (38.5%)
41-50 %	6 (46.2%)

It is important to note that all participants were referred to the study based on the inclusion criteria which specified that the family member was caring for someone with an advanced cancer diagnosis. During one interview, one patient's diagnosis was determined to be end-stage liver disease rather than advanced liver cancer, as indicated at the time of referral to the study. Based on the similarity in the symptoms of advanced liver disease and its round-the-clock care needs, in addition to the family's desire to participate, the caregiver was included in the study.

At the time of data analysis, eight of the thirteen patients had deceased (at home, n = 4; in hospital, n = 4) and five patients were living (at home, n = 4; in hospital, n = 1). Of those that had died, the number of days the patients lived after the researcher's interview visit was calculated. The mean length of days lived after data collection was 28.13 with a large range from three to eighty-eight days.

### **Summary of the Qualitative Findings**

The family caregiver interviews ranged from 50 – 90 minutes in length. The participants described the interview process as a positive experience. It focused solely on the caregiver, allowing each of them an opportunity to 'give voice' to their experience. Study participants expressed the desire to be involved in the study not only for their own interest, but also for the purpose of helping others in the future.

The semi-structured interview sought answers to the following questions:

- 1) How do family caregivers of community-dwelling advanced cancer patients describe their experience of sleep disturbance?
- 3) What factors do family caregivers identify as contributing to sleep disturbance?
- 4) What consequences do family caregivers identify that sleep disturbance has on their ability to carry out their caregiving role?
- 5) What consequences do family caregivers identify that sleep disturbance has on daily living and their own health and well-being?
- 6) What do family caregivers identify as being helpful in managing the sleep disturbances that they experience?

As outlined in Chapter Four, the face-to-face, audio-recorded interviews were transcribed verbatim, followed by thematic analysis. The process of open coding,

clustering, and discussion with the researcher's advisor, allowed the salient themes to emerge. Refer to Table 5.3 [p. 71-73] which presents the major theme, sub-themes, and categories, as well as the operational definitions for each.

**Table 5.3 Summary of Salient Themes and Operational Definitions**

<b>Major Theme, Sub-Themes, and Categories</b>	<b>Operational Definitions</b>
<p><b>MAJOR THEME:</b> <i>Sleeping With One Eye Open</i></p>	<p>Refers to the nature of sleep disturbance experienced and described by-family caregivers, owing to their ever vigilant attention to their <b>relatives'</b> physical and emotional care needs. Caregiver sleep is consequently experienced as being 'light' as opposed to being deep and restorative.</p>

<p><b><u>Sub –Theme I: Factors Contributing To Family Caregiver’s Sleep Disturbance</u></b></p>	<p>Refers to those people, places, thoughts, and events identified by caregivers that singly or collectively contribute to a change in their sleep quantity and quality.</p>
<p><b>Category I: Caregiver-Related Factors</b></p> <p><u>Sub-Categories:</u></p> <p>Psychological Factors</p> <p>Physical/Environmental Factors</p> <p>Social Factors</p> <p>Beliefs About Sleep Debt</p>	<p>The first category encompasses the various factors directly related to the caregiver; it is further divided into the following sub-categories: psychological (emotional/cognitive), physical/environmental, and social factors; and personal beliefs regarding sleep debt.</p>
<p><b>Category II: Patient-Related Factors</b></p> <p><u>Sub-Categories:</u></p> <p>Uncontrolled Symptoms</p> <p>Decline of Functional Status</p> <p>Disruption of Sleep/Wake Cycle</p> <p>Reluctance to Accept Outside Help</p>	<p>The second category includes the many patient-related factors which may contribute to the caregiver’s sleep disturbance. This category is further divided into the following sub-categories: uncontrolled symptoms, decline of functional status, disruption of sleep/wake cycle, and reluctance to accept outside help.</p>
<p><b>Category III: Health Care System-Related Factors</b></p> <p><u>Sub-categories:</u></p> <p>Assessment</p> <p>Knowledge/Acceptance of Services</p> <p>Quality of Care</p>	<p>The third category is comprised of factors associated with the interface between the health care system and the family caregiver; they have the potential to modulate and/or exacerbate the caregiver’s sleep disturbance. This category is further divided into the following sub-categories: assessment, knowledge/acceptance of services, and quality of care.</p>

<p><b><u>Sub-Theme II: Consequences of Family Caregiver's Sleep Disturbance</u></b></p> <p><b>Category I: Physical Consequences for the Caregiver</b></p> <p><b>Category II: Psychological/ Psychomotor Consequences for the Caregiver</b></p> <p><b>Category III: Social Consequences for the Caregiver</b></p> <p><b>Category IV: Consequences for the Patient</b></p>	<p>This theme describes the many consequences that were identified by caregivers resulting from the change in their sleep quality and quantity. These consequences are organized into four categories.</p> <p>This category includes the various ways that sleep disturbance affects physical health.</p> <p>The second category comprises the changes in emotional status and cognitive functioning that are a result of sleep disturbance.</p> <p>The third category reveals the ways that poor sleep affects the caregivers' interactions with others as well as the impacts on job performance in work done beyond that of the caregiver role.</p> <p>The fourth category outlines the consequences of the family caregiver's sleep disturbance on the care-recipient.</p>
<p><b><u>Sub-Theme III: Caregivers' Strategies To Overcome Sleep Disturbance</u></b></p> <p><b>Category I: Getting Through the Endless Day</b></p> <p><b>Category II: Getting Through the Restless Night</b></p>	<p>This theme describes the numerous strategies identified by family caregivers which they used to overcome the effects of poor sleep.</p> <p>This category includes the various methods, both physical and mental, employed by caregivers, to get through long days of caregiving, despite not receiving the usual quantity and quality of sleep at night.</p> <p>This final category includes the strategies utilized by the family caregivers to optimize their night-time sleep while engaged in the role of caregiver.</p>

### ***Major Theme: Sleeping with One Eye Open***

The overarching theme, *Sleeping with One Eye Open*, captures the nature of family caregivers' sleep as described by the participants throughout this study.

In varying ways this night-time state of mental awareness of the patient and readiness for caregiving was described throughout the narrative accounts...

*"Oh I know right away, it's like I got a, it's like when you have a baby, it's like you have a built in detector ... before [my spouse's cancer diagnosis] I used to go to bed and just pass out... he could get up three and four times a night and I never really knew...now he moves and I just sense it, you know it wakes me up right away."*

*"...it's almost like going back to when you have a baby, you know you got the breathing pattern or the breathes, whatever it is, that will bring you out of your sleep to say, junior needs me or oh no, junior doesn't. I'm finding that I've developed that same sensitivity, it's come back, for my Mom...you've got one ear that's caulked for a certain noise, and then when you hear that, the rest of you wakes up and deals with it. As soon as I hear it, I'm in a way other mode."*

Participants used a multitude of descriptors to portray this theme, such as: radar; skim-sleeping; surface-sleeping; alert while sleeping, just at a lower level; tuned into the person beside you; like parenting a new baby; on edge, tense and easily aroused; heightened state of awareness; and constantly listening for the patient. Participants frequently contrasted their current sleep status to their previous sleep status...

*"I used to be able to sleep, you know a bomb could go off, and unless I knew it was coming...I'm not sure I would have heard it."*

*"I sleep lighter than I used to. I don't even know if my REM sleep stage is actually happening because I don't have any dreams... I've noticed that."*

This heightened state of awareness was described even by family caregivers who were not living at the home of the patient and were able to go home to sleep at night...

*"I don't think you get as deep a sleep. You can't really relax, you're on edge waiting for that phone to ring in the middle of the night... and lately it's like, I wake up, you kind of have that feeling, was I hearing the phone? Right away, you*

*become wide awake, because you literally are in, you're in a heightened state of awareness and anxiety. And it takes you awhile to settle down and go to sleep again."*

Despite describing this vigilant type of sleep experience, some caregivers felt they were still able to obtain a relatively good sleep. This was closely tied to the current functional status and level of independence of the patients, the patients' ability to sleep at night-time, and whether the caregivers sleep arrangement had changed. The various factors that contributed to family caregiver sleep disturbance will be discussed in more detail in the following section.

### ***Sub-Theme: Factors Contributing to Family Caregiver's Sleep Disturbance***

Family caregivers indicated that they experienced disturbed sleep across the patients' illness trajectory in varying degrees. However, they indicated that the reasons for poor sleep changed over the course of the illness. For example sleep disturbance was identified at the time of diagnosis ...

*"Well since she was diagnosed, I guess. You know it plays on you. And you're thinking and thinking and, yeah, you're watching over them, eh?"*

*"I think you keep waking up, you might be in a deep sleep, and then, when you're kinda coming out of that deep sleep, subconsciously somethings telling you, to start worrying about him and, you know, how is today's chemo gonna go, or what's the doctor gonna say, or you know, that's always in the back of your mind and I find you don't rest, you're more jittery, and your mind is always going..."*

*"after the shock and acceptance and treatment at the initial diagnosis, there was a period where we slept very well. And then of course, another shock (reoccurrence). Then the sleep pattern changed where, the sleep was not a pleasant sleep, because you're worrying..."*

*"a lot of the problems with sleep were becoming more related to realizing that we hadn't beat this ..."*

Nights were commonly described as encompassing difficulty falling asleep, interruptions throughout the night, early morning awakening, and starting another long

day too soon. Caregivers also talked about having to adjust to short sleep bouts. A full night's sleep was rare due to frequent interruptions. While most caregivers could not adjust to this broken sleep, some perceived that they had learned how to have short, quality sleeps.

Throughout the caregivers' narratives, many factors were cited that lead to family caregiver sleep disturbance. The theme, *Factors Contributing to Caregiver's Sleep Disturbance* is made up of three categories, Caregiver- Related Factors, Patient-Related Factors, and Health Care System-Related Factors.

#### ***Category I: Caregiver-Related Factors***

The Caregiver-Related Factors Category is comprised of three sub-categories, Psychological Factors, Physical/Environmental Factors, Social Factors and Beliefs About Sleep Debt.

**Psychological factors.** This sub-category is characterized by the notion of 'the mind is always working.' This phenomenon of having a busy mind made it challenging to fall asleep at bedtime, return to sleep when awakened in the night, or maintain sleep early in the morning. Caregivers identified numerous topics and thoughts that re-circulated in their heads. They also expressed the desire for a remote control that offered them the ability to put their mind on 'pause' or 'change the channel,' allowing them the opportunity to sleep.

Thinking and worrying about the patients' status, symptom management, care and comfort were always at the forefront of their minds. Caregivers were bothered by: whether they should keep their loved one at home or consider alternate placement, whether they would be able to keep them comfortable and safe, when death would occur

and not wanting the patient to be alone or unattended. These thoughts are reflected in these caregivers' comments...

*"to keep him comfortable, that is very important to me, will I be able to keep him comfortable?"*

*"...then my sleep pattern changed where, the sleep was not a pleasant sleep, because you're worrying ... my mind was just working a mile a minute..."*

*"...she wants to stay home. Now I've given her six more months at home. But I, I just don't know if I [can continue], she might have to go into, I guess a nursing home or palliative care, or something. I really don't know."*

*"Well, I just feel so very much responsibility, that I have, two sick sisters, in my home, and uh, I wouldn't want anything, to happen... I hope I have some warning, before she passes away, that I can be with her."*

Some caregivers had worries regarding their employment outside the home, and their ability to keep working in the midst of caregiving. For others, financial concerns contributed to their level of stress. These caregivers' comments illustrate these worries which contribute to sleep disturbance...

*"...you know that is still my job, I still have to go there. And do my job. I can't slack off. You know. Um, but it, you know, sometimes, like even today I'm thinking, I don't know how much longer I can do this..."*

*"... yes with finances too, I'm concerned because, he told me that when he goes, his pension will be finished and he said then I can't stay here [in their home] ... over the course of his illness we have used pretty much our life's savings."*

A multitude of emotions contributed to the caregivers' inability to sleep. Guilt was a common emotional reaction amongst this group. The sentiment such as 'if I could just close the door or put in ear plugs and go to sleep' was counterbalanced by the worry of not hearing the patient when need be and thus, feeling guilty...

*"At first I was able to close the bedroom door, when I stayed here, but I can't now, I have to be aware of what's going on. If I do, I find that, let's say, this morning, I must have slept, and she was up quite a bit and I noticed that she was into some pills and then, I felt guilty because I didn't hear her."*

Decision-making, or aptly titled by one family caregiver as ‘mental-filing,’ was a constant factor which kept the caregivers’ minds working. The decision making process was predominantly focused on making the best decisions on behalf of the patient, whether the decisions related to symptom assessment and management, comfort and safety, advance care-planning, sleeping arrangements, equipment needs (i.e., whether a hospital bed should be ordered?), accepting outside help, or place of care. This constant decision-making was woven throughout the caregiver narrative...

*“Last night having come home from, helping her get ready for bed...seeing how yellow tinged her skin was... and knowing full well I mean this is jaundice, it’s just another level of her cancer. I went to bed at midnight. I gave up the fight to fall asleep at 1:30, came out here and read for an hour, went back to bed, couldn’t sleep, it was just going over and planning my days out when really I should be sleeping. You know, I’m gonna have to make arrangements to call home care. I’m gonna have to make arrangements, to do this and start that... and once you start that mental filing...forget falling asleep.”*

*“Yeah, and I’ve been starting to question myself if, if it would help to get a hospital bed? or if it’s time to put him in the hospital? ...some difficult questions...”*

*“When it comes towards, like the end of life where he would stop breathing, and we talked it over he and I when we were by ourselves for a while and I thought he was fairly clear in his thinking, and we filled it [health care directive] out together, but then he didn’t sign it... I don’t know what his thinking is about that. I know many years ago we discussed it when we were filling out our will...and we both said we didn’t want to be resuscitated if it came to that point... I can’t see anybody doing CPR on him with his frail body ...”*

Decision making also encompassed the caregivers’ self care needs. Caregivers recognized self-care as critical in sustaining the caregiving role yet it often remained as elusive as a good sleep ...

*“At first, ...for about two months, I didn’t have any home care. I was being a martyr. And then I thought, no, you’re gonna burn out.”*

*“So, I explained to my husband, it’s not because I don’t love him. It’s because I do love him that I wanna be healthy. And if I have to do banking, I have to do the groceries, or have a rest...and I cannot do this if I am here... so the respite is I think going to do good things for me ... So I take care of my first prime concern, my husband, and then I take care of myself as well.”*

The degree to which family caregivers were able to discuss and problem solve with others, including the patient, family members, or health care providers, seemed to determine or affect the degree of impact decision-making had on sleep disturbance. Family members who shared the caregiving role with other like-minded family members, stated that it made a tremendous difference to have one another for shared problem-solving and decision-making.

Another component within the psychological factors that troubled caregivers and contributed to their problems sleeping, was anticipatory grief. Anticipatory grief is interwoven throughout the illness trajectory. This grief includes the many losses that are experienced by the patient from the time of diagnosis, such as the loss of health, the loss of treatment options, the loss of functional status, the loss of future, and the loss of life. While the caregivers experience many losses as well, which many include the loss of a partner, loss of income, loss of security, loss of future plans together, and so on...

*“but I start thinking about how, the sadness I feel in not being able to communicate [with my husband] and the loss the relationship... we’ve been married for, forty-two and a half years.”*

*“what it’s gonna be like afterwards... that’s something else that I think about...I want to be realistic. I mean my son said to me, Mom, you sound like you have given up...I said no, but I have to be realistic and I have to be able to grieve now...otherwise if I don’t, I don’t know how I’m gonna cope... I said I have to talk about it... and, at this point it’s not possible to talk to [my husband] about it anymore. Yep. We have not kept secrets from each other. We have always talked to each other and I think maybe, that’s why our marriage was so good...”*

*“It’s hard to fall asleep. Um, because it’s my Mom who’s basically...[dying], we have been very close, so its hard to come home after looking after her...you don’t*

*feel comfortable, really just letting go with the grief and you know, sobbing or crying at her house...so when you do come home at night...you have to take that time to mentally debrief... you sit there and maybe I, you weep, you cry. Because you know its coming and there's nothing you can do about it."*

In this category, many examples of psychological factors that contribute to sleep disturbance have been presented. It is evident how this menagerie of 'thoughts' overlap, intertwine, and play on the minds of these family caregivers, while challenging their ability to obtain a good night's sleep.

**Physical and environmental factors.** Many physical and environmental factors were identified by family caregivers as contributing to their sleep disturbance. In the majority of the situations examined in this study, there had been some alteration in the physical sleeping arrangement in the home. Either the patient's location had shifted to another room within the home, the patient was sleeping in a hospital bed or had additional equipment such as an oxygen concentrator and alternating pressure mattress. These physical changes often created unfamiliarity including different noises and light levels...

*"So a comfortable home environment with a hospital bed [in the living room], special mattress ...he wants to be able to see outside... and to be central and know what's going on... I sleep here on the couch... and we set the concentrator in our bedroom so it's not as loud in here."*

Along with these many changes was the fact that life-long partners were no longer sleeping together...

*"We fixed up a new separate room for him, close to the bathroom, ...[the change] alters how I sleep because that void of somebody being there with you all the time, and then, then there's also the knowledge of that somebody [spouse] ...is many feet down the other end of the house, who is very ill."*

When family members were away from their own home, staying with the patient, there were often environmental differences which hampered their ability to sleep...

*“Well I guess, you know I can’t seem to get used to the single bed. And that, you know, it’s not my bed. And uh, the smoking, she’s [the patient] a smoker. I’ve never smoked. So sometimes you know, I get up and she’s had a cigarette, or she’s already been smoking a lot in the evening, and my throat, my nose is congested, and you know I’m not getting a restful sleep. At first, I closed my bedroom door...but now I can’t, I have to be aware of what’s going on.”*

*“I’m sleeping in the corner [of the living room] over there... yeah, there’s a lot of difference... And [my home] is in the country right, so I don’t have street lights and any traffic noise...sleeping here I’ve got street lights that shine right into my eyes... at home I’ve got a queen size bed, plus this one [single bed], it’s old and sags and feels lumpy.*

Many of the family caregivers utilized a baby monitor to facilitate communication between the caregivers and care-recipients, in case the patient required help in the night. These monitors were viewed as a mixed blessing by the caregivers, as they reported that *the smallest noises* of the patients or other caregivers was audible at the caregivers’ bedside. Even when family caregivers had over-night respite service, they used the baby monitor to ‘stay-tuned’ with the patient’s situation...

*“She doesn’t necessarily sleep, all night, and I, I can hear that, with the monitor. I guess the monitor does kind of, disturb my sleep a little bit, because I can hear things quite a bit, but I manage with the sleep I get, even if it’s limited.”*

A unique term mentioned by a number of caregivers was ‘couch night’. This involved their assessment of the patients’ status on a daily basis. This assessment determined their proximity to the patient throughout the night. If the patients’ were deemed to need more physical assistance, supervision, or emotional support, the caregivers’ chose to sleep close by, often on the chesterfield. The following exemplar is representative of the caregivers’ descriptions of this concept throughout the narratives...

*“So I have to judge how she is before I go to bed, see if I can go to sleep without worrying... you know, sleep back in bed, or, or is it a couch night, and if I sleep on the couch, I hardly get any sleep...”*

Another contributing factor to sleep disturbance mentioned by family caregivers, which bridges the physical and psychological sub-categories, was the loss in sexual intimacy. The following quotes from spousal caregivers articulate a significant loss in partners' typical bedtime routine...

*“now he has his side of the bed elevated because of his heartburn problem, so he sleeps higher...I'm down there, and he's up there...and he also has to have a pillow at his feet, to raise his ankles up... so that's the only thing that's kind of different on his side of the bed, but, you know, and I can't, get as close as I used to...so all we can do is hold hands...”*

*“There is something that is very personal...I wondered about when they are terminally ill, what can be done sexually...the person's still, you know still has desires but is unable to do anything about it, and we have always found that very satisfying, even to go to sleep afterwards...I am wondering if that is making him restless, I don't know.”*

**Social factors.** Throughout the interviews, the caregivers spoke of social circumstances which were deeply connected to the sleep equation. The two most common factors which emerged were the caregiver's current employment status and family dynamics. As noted earlier, trying to meet the demands of a job as well as that of fulltime caregiver was very stressful and tiring. This was particularly difficult for family caregivers that work varying shifts...

*“Where it is gonna get difficult, is um, I'm gonna be on days for two weeks... but then ...I'm on evenings for two weeks. And then, I do a week of nights. Home care hasn't been covering nights... just cover my day and evening shifts, or when I am sleeping during the day after working nights. I guess my daughter will probably come and spend the night here.”*

Caregivers talked of family members who were helpful or not helpful in sharing the caregiving role. As noted earlier; shared family caregiving was often a very positive experience that perhaps buffers the stress and sustains in-home care. Family caregivers indicated that they could create opportunity for respite and sleep for each other. When

this reciprocal family relationship was not there, family caregivers experienced severe sleep disturbance...

*“[I] felt like I was being taken advantage of almost, you know. As long as I’m here and whatever. So I had to really sort of start talking and say okay, this is what’s going on for me. I need to sleep, I was, I am very sleep deprived... but, every time I tried to says something, they shut me off. They didn’t want to hear, you know, so I just said, well whatever... kept feeling like I can do it, I can do it, then all of a sudden, you know I couldn’t...”*

**Beliefs about sleep debt.** It was not unusual for family caregivers to minimize their sleep disturbance whilst caring for a loved one. They conveyed the belief that they could manage with less (e.g. one good night’s sleep per week), that they were getting enough rest for now, or that they would recoup their sleep loss at a later date...

*“I sort of sacrifice myself at this point, I’m not as important here. Right now. I do feel I have enough sleep. Because even if I don’t sleep soundly, at least I’m reclining. And you know. I’m resting... So if I’m not sleeping well. That happens sometimes. Then I make up for it the next day or so, the next day maybe I’ll sleep better.”*

*“Actually I’m pulling double duty...and I say, God I need a break... but I guess part of your mind just sits there and says, that’s the way it is right now, so deal with it. And I figure that, I’ll take my time to, sort of fall apart and go into a bit of a recuperative coma, you know, once everything is done and my mother passes away.”*

This section has summarized the salient caregiver-related factors contributing to sleep disturbance, that emerged in the analysis of the caregiver narratives. These caregiver factors are closely interwoven with those of the person they are caring for, the patient-related factors.

### ***Category II: Patient-Related Factors***

In this section, the patient-related factors that contribute to the family caregiver’s sleep disturbance, will be presented. It was repeatedly articulated by the family caregivers that ‘if the patient sleeps, I sleep’. The main factors associated with this category are:

uncontrolled symptoms, the patient's placement in the illness trajectory, the decline in the patient's functional status and level of independence particularly in relation to toileting and incontinence, disruption of the patient's sleep/wake cycle, and the patient's reluctance to accept outside help to relieve the family caregiver.

**Uncontrolled symptoms.** It was evident that if the patients' symptoms, especially pain and delirium, were not well controlled, this had a direct impact on the caregiver's sleep disturbance...

*"[It] depends on how he is feeling. Like on Sunday, just before we got this [new medication] order, he would be just moaning and moaning. You know so, then I wasn't sleeping. I was, we were, up more than three or four hours. You know, cause I mean, you just can't handle it all, you know. I'd give him the extra morphine and it wasn't working. And that's the hardest thing, is watching your someone suffer...I would just pray that he would go. You do, you know."*

*"she's up and down all night- very restless, ...so you're putting her into bed and she's out of bed, and then into bed and, you know just lifting her legs, if her legs are bad, she can't get her legs into bed, so she is back and forth, so you're helping her back to bed all night long..."*

Night-time routines were also dictated by the medications that needed to be given for symptom relief. For instance, caregivers' commonly were up in the night to administer analgesics...

*"My head hits the pillow and I'm out, but I could be awake again within an hour, if my husband has to get up. We have been giving his morphine at midnight. Usually we're awake by then, he comes in the kitchen, has a glass of water, takes his pills and we go back to bed."*

Even when night respite is in place through the Palliative Care Program, family described how the night workers would need to wake them to administer the pain medication which reverted them into the caregiving role and the reality of the situation in the middle of the night. It was also acknowledged that the assessment and treatment of the patient's symptom of sleep disturbance was an important consideration. Only a couple of the

patients involved in this study were prescribed a night-time sedative. For those taking medication to promote sleep the caregivers reported that the patient ‘slept quite well’ except for nocturia.

Family caregivers also described situations where the patient’s anxiety influenced their sleep. While one caregiver shared how the patient had a strong Christian faith, an acceptance of death and her daily prayers asking God to take her to heaven, others believed that it was the patient’s fears or anxiety that created sleepless nights for both the patient and the family caregiver...

*“He used to be up a lot more because I think he was afraid ...he wants to get up and have tea during the night, I mean a one or two hour session...I’m sitting there at the end of the table and a lot of times, he sits down there and sleeps basically, but he doesn’t want to go back to bed.”*

**Decline of functional status.** As the patients near the end of life, their functional capacity and independence declines. The study findings re-iterated the significance of functional decline on the caregivers’ ability to sleep. As soon as the patients required assistance with toileting, whether this meant assistance walking to the bathroom and back, transferring to a commode, or changing soiled clothing and linen due to incontinence, the caregivers’ sleep was interrupted. Night-time activity revolved around the patients’ toileting routine. The following narrative represents the caregiving experience shared by many...

*“She’ll tell me she has to go. So then I’ll take her and then take her back. And then, she’ll turn around and wake me up, and tell me she has to get up again. Yeah. So it’s that kind of assistance, kind of personal assistance there and back and getting her comfortably back into bed. So by that time, you’ve woke up, you can’t get back to sleep again. You know how it is?”*

Often, this functional decline also translated into the family member caring for someone who was now incontinent, required assistance with re-positioning, and regular skin care

throughout the day and night. At this stage, the caregivers who did not have overnight respite, described sleeping on the couch, close to the patient, and acquiring little sleep. One caregiver anticipated this change based on her previous family caregiving experience...

*“If the time comes that I have to assist her more, change her and turn her, which I find very important, so she doesn’t get bed sores, or anything like that...so then, I’ll probably sleep on the couch. Yeah.”*

Closely related to this notion of patients requiring increasing care at night, was the length of the caregiving tasks. Family members indicated that the longer they were up tending to the patient’s needs, the harder it was for them to get back to sleep. The following narrative demonstrates this challenge as the nightly care demands increase ....

*“Whether I can [go to sleep again] depends on how long I’ve been up with her, like if its going to the bathroom, helping her to change if she’s been incontinent, ...anything like that that takes anything more than maybe a couple of minutes..., you know just getting her legs back in bed is one thing, but [helping her in the bathroom and back to bed] that takes maybe about half an hour to forty-five minutes, than I’m awake, and I can’t go back to bed.”*

**Disruption of sleep/wake cycle.** Another patient-related factor which contributes to caregivers’ sleep disturbance, is disruption of patients’ sleep/wake cycle. For example, caregivers identified that patient drowsiness secondary to medication regimes, compounded by a lack of activity due to functional decline, leads to patients sleeping more during the day and not during the night. The following quotes from spouses demonstrate this common problem in palliative care...

*“Now he’s up more in the night, because he dozes a lot in the daytime so he get up in the night time when he’s slept out.”*

*“Its just that he, he gets his sleep all messed up, cause he sleeps a lot during the day sometimes and a lot of times if I go to work for the evening shift, the home care worker will let him sleep the whole shift... until I get back at midnight.”*

**Reluctance to accept outside help.** Another patient-related factor which contributes to caregivers' sleep disturbance is the patients' reluctance to accept outside help. Help, commonly referred to as respite care, creates the opportunity for family caregivers to have a break or sleep during the day or night. The patients' perspective certainly influenced whether family considered or accepted this type of overnight or daytime assistance...

*"I know she doesn't like when I have respite, ...she says I don't want anyone sitting in my room...so I'm not sure about night help."*

*"Sometimes, my dad is really demanding, yet he says he doesn't like home care... So I tell him the nurses are coming in every day to stay with him, but it is actually a home care worker. He doesn't know the difference but it gives me a break to have someone come."*

It was evident throughout the narratives that the patients' status- physical, emotional, spiritual and social – was closely linked to the family caregiver's ability to sleep. This section has provided a number of examples that illustrate this relationship.

### ***Category III: Health Care System-Related Factors***

Other factors which were identified as contributing to caregiver sleep disturbance were associated with the interface between the family and the health care system. The three main sub-categories that emerged were *Assessment, Knowledge/Acceptance of Available Services* and *Quality of Care*.

**Assessment.** Only three of the thirteen family caregivers had discussed their tiredness and sleep problems with their family doctor, two of which were prescribed sleep medication. Their first line of communication was most commonly with other family members, and secondly with either the Palliative Care Coordinator or the visiting nurse.

Caregivers did not indicate that health care providers inquired into their sleep status, and most felt it was not something that they would consider reporting...

*“Umm, I would probably discuss it with [my daughter], or something like that, I don't, yeah, I can't see myself talking to somebody about something like that [sleep]. This is the way it is right now, not much they can do ...”*

This lack of reporting seemed to hinge on the families' beliefs about sleep debt.

An employed family caregiver pointed out that it was difficult to connect with the visiting nurse as the nurses' visits coincided with the caregivers' time at work. This caregiver and others indicated that their line of communication would be with the palliative care coordinator...

*“...she is the one that could bring, or, tell me what resources were available. I'm assuming that is where I would go if I needed to.”*

*“... I think [the palliative care coordinator] is one fantastic lady. She and the nurses at oncology...they are just a phone call away...”*

While most caregivers indicated they would probably not voluntarily report their sleep problems, they acknowledged that certain visiting nurses had the expertise and intuitive assessment skills required to pick up on sleep disturbance and intervene appropriately...

*“...they are the ones that I would, truly feel are listening, and being able to really hear what I'm saying and maybe I'm not saying. Maybe I am not saying I just can't sleep, maybe I'm really saying something else ... and they can focus in on [what the problem really was].”*

*“this one particular [nurse] ...she asked the right questions, at the right time... and now and then I did talk to my doctor, and you know what, ... she said it was okay to increase [my sleep medication] a little bit.”*

These exemplars help to demonstrate the families' perspectives related to the assessment and reporting of their sleep disturbance during palliative caregiving.

**Knowledge/acceptance of services.** Family caregivers raised the importance of being informed about the range of services available to them, the criteria, costs, and timing associated with such supportive services. Caregivers also stressed the importance of clear communication from home care regarding the service plan, availability or changes. They stressed that this information should include how and when family could communicate back to the Palliative Care Program about how the respite service was working for them and if the health care workers were a good ‘fit’ for the home situation. A family member who desperately relied on the breaks from caregiving to catch up on sleep, found the uncertainty of servicing difficult...

*“its been a bit of a struggle, because I will arrange something, and ... I thought they were gonna be here on the weekend, and they didn’t show up... need better communication.”*

While other family caregivers were unclear about when and what to report regarding the night respite that was arranged in the final weeks of care for their loved one...

*“I think what the key thing is from palliative care services, is that they have to let the caregivers know what the expectations are for the care workers and that it’s okay to voice your [feedback regarding the workers], ... cause you do not want to jeopardize, you don’t want to say anything because what if they pull everything out, and I’m thinking this is palliative care, you know, .... my mom didn’t even want to sleep, she didn’t wanna close her eyes, you know, because she didn’t trust her.”*

The worry of jeopardizing the service available to them through home care, placed family caregivers in a difficult spot. If the worker was not a good fit for the patient and the family, both were unable to sleep, defeating the purpose of the over-night respite. Yet families hesitated to provide this feedback to the coordinator, fearing the consequences. This concern serves as the segue to the next sub-category titled, *Quality of Care*.

**Quality of care.** The last sub-category under Health Care System – Related Factors relates to the quality of in-home care. It was apparent that for respite services to be effective, they have to be of a quality that instills *trust* and *acceptance*. These qualities allow the family caregivers to hand the care of a loved one over to a stranger entering their home. Family caregivers eloquently described the decision making process entailed in releasing the care responsibility to others...

*“...having the overnight staff, I think the quality of sleep you’re gonna get there, is dependent on the individual staff person that you have, and the family’s ability to let go, um, I think that would be key, the two key issues... Is [whether] you’re comfortable, cause I mean we had one overnight staff here, and I wouldn’t close my eyes... so, I guess for sleep for the caregivers, within your program, the criteria for us as caregivers would be the confidence-ness of the staff that’s here at night, and the family’s ability to let go, and let somebody else, take and do, otherwise, I can’t sleep anyhow.”*

The quality of care which facilitated family caregivers’ sleep was also equated with the continuity or consistency of health care workers entering the home. Family caregivers stressed the difficulties encountered when new faces arrived to help each shift, as this meant they would need to be involved in orienting the worker to the home and care of their loved one rather than sleeping...

*“When we were getting new people all the time, and some workers were sick...I ended up having to stay up all the time because you had to give them a routine.”*

Many family caregivers stressed the importance of health care workers being capable of working to their full scope of practice. They reiterated the importance of the home care worker’s ability and initiative in assisting with personal hygiene, assisting with linen changes and patient laundry. If the patient was still lucid and communicating, they reinforced the importance of workers providing the necessary conversation and stimulation that the patient needed while providing respite. These points were illustrated

by family caregivers' frustrations and disappointments in some experiences with respite services...

*"Its just that he [the patient] gets his sleep messed up, cause he sleeps a lot during the day and when I go to work [in the evening], the home care worker will let him sleep the whole shift... if [the patient] has no one to talk to, to keep him up, he'll just snooze ... and they let him sleep 'til I get back at midnight. So that's upsetting. Others will come and they watch TV together all evening, [the worker] falls asleep, [the patient] will fall asleep...It would be nice if they could do more of his care while they are here rather than telling me he needs a bath when I get home. [One home care worker] is a different nationality so that communication is a big problem... so instead of communicating...they just do their own thing...if you ignore him, he's gonna sleep, if you try to communicate with him and talk to him, he'll stay up til about 10:00 at night. But I don't want to say anything, as I want them to come and keep him company and give me a break."*

### **Summary**

This section has highlighted the categories and sub-categories of the theme, Factors Contributing to Family Caregiver's Sleep Disturbance, providing exemplars from the caregivers' narratives. Caregivers described how sleep was a blessing if it represented the quality and quantity needed to be restorative but also offer a desired reprieve in the midst the lived reality of palliative caregiving. However, for many, while sleep was more necessary than ever, it was often described as elusive and therefore the nights became dreaded.

#### ***Sub-Theme: Consequences of Family Caregiver's Sleep Disturbance***

Many of the family caregivers indicated that they had not considered the consequences resulting from sleep disturbance, yet, were very quickly able to name the ill-effects they experienced after a bad night. At the end of the research interviews, a number of caregivers recognized that the questions had spurred them to consider their personal consequences more fully...

*"There's actually a few things... I never really looked at it like this before."*

This section presents the consequences of sleep disturbance identified in this study, under the four categories, *Physical Consequences for the Caregiver*, *Psychological/ Psychomotor Consequences for the Caregiver*, *Social Consequences for the Caregiver*, and *Consequences for the Patient*.

***Category I: Physical Consequences for the Caregiver***

The most common physical consequences identified by family caregivers, were feeling very tired, drastic changes in their usual routine especially around exercise and food intake, and the experience of daytime sleepiness. Every caregiver interviewed commented on the degree of tiredness that they experienced, as illustrated by this quote...

*"...Cause like right now, I'm real tired. My eyes are tired, they're heavy, but I know I won't be sleeping until later tonight, maybe midnight."*

This tiredness translated into lack of energy to do what needs to be done around their home, beyond the patient's care...

*"When I go home to my own home what is affected it that I get in my house, and I can't do anything, I can't function, and so my house is a mess...like even the laundry. You know I am trying very hard but the rest, I let a lot of the rest just go."*

They also linked the tiredness to feeling unwell physically or personal illness...

*"You know by the end of the week, by Friday, I'm gonna be... well once I got sick...I'm recognizing that now, is that I need to have that [sleep], or I'm not gonna be able to do this much longer, and I can't afford to get sick again.."*

*"Well, I was getting a real nervous stomach. You know it plays on you. My stomach, got nerved up, and it kinda whips ya, eh?... It's all over, it's your nervous system, yeah."*

*"I have been getting more headaches, maybe that's related, I don't know."*

Family caregivers frequently associated limited exercise and weight gain with the diminished energy and motivation experienced with poor sleep. A caregiver who was currently living with the patient and not in her own home expressed these changes...

*"I've put on weight. ...[at my own home] I live about an hours walk from work. I used to walk back and forth to work. So I feel like I don't now. I sort of got out of that routine. And the food, I guess I make for her, soups, puddings, an stuff like that and, you know I don't make really, anything different for myself...I'm eating things that are just totally different than what I'm used to... [I] just don't have the energy to prepare food for myself separately."*

In contrast, some family members described a loss of appetite or decreased interest in food, and felt that they had lost weight...

*"It's having an effect on me physically, just because I can see how it's effecting other people physically, so obviously it has to effect me too, in what ways, well, I'm losing a bit of weight...I usually use an exercise ball and part of it's motivation to, to be motivated to do things physically, you know, it's all connected."*

Another significant consequence of disturbed sleep described by family caregivers was daytime sleepiness.

*"I do find myself falling asleep, sitting on a chair, and sometimes... if the girls [young daughters] go down for a nap, I'll lay down with them and then I'm falling asleep before they do."*

*"If I sleep on the couch, I hardly get any sleep, and this was happening before...I was hardly getting any sleep, and that's when I was closing my eyes on the way home, or even on the way to work, I was, you know, I'd come to a stop sign and my eyes would be closing. So that was kind of scary."*

Even though all caregivers described having 'busy minds', the degree of sleepiness they were experiencing was evidenced by the fact that they could still fall asleep relatively quickly. They described being so tired, that they reached the point that they could fall asleep despite their worries...

*"Well by that time, I am so tired, there is nothing that can stop me from falling asleep, absolutely nothing."*

***Category II: Psychological/Psychomotor Consequences for the Caregiver***

The most immediate and consistent response from caregivers when asked about the consequences of poor sleep, had to do with its effect on their emotional status and mood. They described feeling a wide range of emotions such as grouchiness, impatience, irritability, crying easily, 'kind of down', angry and having a fast temper. They commonly referred to these feelings using terms such as 'I felt like I would crack' or 'go crazy'. Many of these feelings are contained in this description...

*"I think that when you don't sleep properly, you're just not, I'm just not me, ... I don't know if you want the word tolerant to handle a little bit of changes and stuff... more reactive to situations, you know, like especially...dealing with my Mom, if you see where her pain level or discomfort is increased, ...let's give her something, what can we do, ...I think for me there's just some missing ability to cope the same or deal with other people... less patient... My anger is always a result of something else, right?... an accumulation, lack of sleep, yeah... really good words here [would be] intolerant, reactive, explosive."*

In narratives like the one above and the following, caregivers recognized that they are less able to cope due to tiredness...

*"Sometimes I do feel like, my plate is a little full. I do feel that way sometimes, but that might be also sleep-related..."*

Some of the family caregivers touched on a sense of depression in their conversations.

Yet it was difficult for them to discern if this was merely a result of disturbed sleep or a combination of the overall experience of caring for a loved one at the end of life...

*"you don't have the energy to enjoy the things you used to...you're not as peppy or as bubbly, so you know it does, if affects your mood"*

*"Friday at work, I felt like, well my boss has a barometric pressure gauge, but I don't think that's what it was, I felt like something was sitting on me. It was just, I felt just that awful feeling, like, I can't move. So, just a real heaviness."*

They also identified that poor sleep impacted their cognitive functioning, in terms of concentration, memory, ability to read and write properly...

*"I find my concentration abilities are just gone to heck in a hand basket...I'll be heading into a room, half way there and thinking why was I going there... so, I don't do anything that requires serious concentration."*

The changes in their cognitive skills were particularly troublesome for those caregivers who were still working, as they noted changes in their job performance. Caregivers shared work experiences that illustrated the impact in this area...

*"... at work, I was trying to write as we have to write notes. I would write notes and then I go back and read them, and go, what the heck is this?... I couldn't even understand it, or people [work colleagues] are drawing attention to like what's this, what do you mean by this?"*

*"I find myself napping at my desk...this may seem absolutely hilarious but I have had my fingers on the keyboard, and fallen asleep and then had a whole page of x's or zero's...then I say okay, how long did it take me to do that, that must of been a couple of minutes nap."*

### **Category III: Social Consequences for the Caregiver**

Many of the caregivers recognized the social implications of poor sleep. They did not have the energy to maintain contact or relationships with others - family and friends...

*"Giving care all the time...yeah, you don't feel like coming home and, getting on the phone or, would you like to go out for coffee, so, there's a lot of people I just haven't talked to in months."*

*"I think of my relationship with my own daughters, we're not seeing as much of each other, and I think what was happening before, I was going home, and the place is a disaster and I was throwing a fit... so that has strained my own relationship with my own girls at this rate."*

Throughout the transcripts the pendulum swung from the sense that their 'life was on hold' verses 'life continued to unfold'. While some rationalized that they would catch up on the social interactions in their life after the caregiving period ended, others recognized that they needed social contact to sustain them through this period, and others had no choice as many other life events unfolded with no sense of control. A number of the

families interviewed, had family deaths or illnesses simultaneously with this caregiving period, adding to the complexity of the psychological factors that contributed to night-time wakefulness. Amidst the array of negative consequences of disturbed sleep, a couple of very optimistic and positive-minded souls rationalized the benefit of being up through the night with a loved one as the opportunity to spend more of limited time, together.

***Category IV: Consequences for the Patient***

The family caregivers' sleep disturbance has the potential to create consequences for the patient in various ways. The family members recognized that poor sleep may affect the quality and feasibility of home care for the patient, as well as the quality of the relationship between themselves and the patient.

Caregivers identified that disrupted sleep altered their emotional state and how they interacted with the patient. Some expressed concern that it may negatively impact their relationship with their family member who they were caring for...

*“you feel bad sometimes that you might be shorter, or a bit irritable... a few times when [he has been incontinent], I snapped you know, like why didn't you, you know, ask me to help, and then I felt terrible and I apologized after but...”*

*“So at first we were able to connect and do things together and have time together, and I hope that it doesn't come to the point where I do something that harms that [relationship], you know.”*

The quality and safety of the care they offered the patient, as well as their ability to continue to provide in-home care was definitely affected by their ability to attain sufficient sleep. This was apparent in many of their narrative accounts...

*“I have pulled back...I could hear her up, and I just went, oh, I can't get up. I can't get up. And I just lied there, ... but then she goes to the bathroom, and I listen... If I go help her into bed she'll sleep better, or if she can't get in, she falls backwards and she can't get to sleep... with her legs positioned or pillows positioned, and so she's up all night. So, yeah, I'm not giving her the care she needs during the night.”*

*“I’d put out her pills but I would forget to give her pills in the evening. Um, it is just like mid-sentence you draw a blank, and then they [the patient] look at you and you realize what you’ve done.”*

*“Because if I don’t sleep, I won’t be good during the day...and then how will I function looking after my husband?”*

*“Well I feel that if I don’t sleep, then I can’t care for him effectively – I worry that if it’s too long of not sleeping then it’ll get worse, and I won’t be able to give him the care that I want to give him... which may affect my decision about whether he goes to hospital or stays home.”*

It appeared that these thoughts and concerns entered into a vicious psychosocial cycle.

Worries regarding whether in-home care would be possible were exacerbated, which translated to feelings of regret and guilt, and these emotional reactions compounded and perpetuated the ‘busy mind’ syndrome, identified under *Factors Contributing to Family Caregiver’s Sleep Disturbance*.

#### ***Sub-Theme: Family Caregivers’ Strategies to Overcome Sleep Disturbance***

The current study posed the research question: What do family caregivers identify as being helpful to them in managing the sleep disturbances that they experience?

Throughout the analysis of the family caregiver narratives, the theme, *Strategies to Overcome Sleep Disturbance*, emerged. This theme was clearly divided into two categories, *Getting Through the Endless Day* and *Getting Through the Restless Night*.

These two categories characterized the 24-hour sleep and wake cycle experience of the family caregivers. *The Endless Day* of family caregivers typically started too early, was filled with a hectic daytime schedule which left limited time for ‘self’ and ended in the late evening. *The Restless Night* was frequently too short and interrupted. One couple described how they intentionally went to bed earlier, with the hope of achieving *enough* sleep given the longer time period. The caregivers shared strategies they had tried to help

them get through these sleep deprived days and tiring nights. This section summarizes these strategies.

***Category I: Getting Through the Endless Day***

All the caregivers described their days as ‘too busy to think about being tired,’ and few allowed themselves an intentional nap. The days were quickly consumed with the coordination of care and caregiving tasks for the patient, care of other family members, work if the caregiver was employed, household tasks like laundry, shopping, and meal preparation, as well as the many roles and duties assumed from the patient. One woman described how her husband was a carpenter, in the midst of renovating their home at the time of his diagnosis. Therefore she became a carpenter and general contractor as well as caregiver, to see the project to completion. The following narrative depicts a typical early morning that initiates the long day which doesn’t end until ten o’clock in the evening...

*“We go to bed at ten, and get up at four, as I need to be at work by eight...I shower, do my hair and makeup...make breakfast, which is always sausages, eggs, and hash browns for my husband...he likes to have a good breakfast and it’s the only good meal he still eats, so we still do that... I try to get out of the house by 6:30. I go to my husband’s office to feed the security dog and take him for a walk... I try to be on the road by 7:30 to my office... and that’s the way it is every morning of the week.”*

The caregivers described the various ways they tried to compensate for their tiredness after early risings. Consumption of caffeinated beverages varied between caregivers. Some chose not to use coffee, tea, or soft drinks at all or intentionally limited their intake to two cups in the morning, recognizing that caffeine may cause additional sleep problems. While other families who historically drank coffee morning, afternoon, and night, continued to do so as they reported that it did not prevent them from sleeping.

Many caregivers identified that they nibbled or binged on food to keep themselves going...

*"I find, that in order to stay awake sometimes in the afternoons, I have to nibble...yeah, a little thing like a bag of peanuts, and I just eat one at a time...you know, that does keep me awake, if I'm nibbling on something very small, it takes a lot of effort."*

*"Another thing I do, is eat, I binge eat, to keep myself going."*

Two of the caregivers had accessed respite service to assist with the patients' care while they were at work and four of the thirteen had respite service during the week days to provide them an opportunity to rest, do errands or have a break away from the home. For the most part this daytime respite was a very positive strategy...

*"I have my respite in the afternoons, I go out and sometimes I have a book along and I park myself in the park somewhere just to get away, and I read, and sometimes I get tired, so I just put my car seat back and have a little snooze."*

Some caregivers planned a nap at a regular time to ensure they had the energy to fulfil their activities and responsibilities of the day...

*"I have a nap, usually between one and two [in the afternoon] and then I go to work at three...but that way, I feel refreshed."*

*"Well what I'm doing now is trying to take a twenty minute nap...like at work, when I feel that I need it and it is okay to do so...or when I get home from work before I make supper, I just need to lie down..."*

While others found this strategy of napping did not work for them...

*"No. I've tried but that doesn't work. I mean that's when I go to sleep and don't hear anything...if I sleep during the day, I'm down for the count, and I've gotta have at least two hours, or when I wake up, it's like walking through molasses."*

There was a variety of strategies caregivers employed throughout the days to keep themselves going. They credited everything from family support, faith in God, prayer,

reprioritizing activities, or creating a 'break' for themselves. Examples of these breaks included fresh air and exercise even if it was a short walk around the block or out in the yard, working on a puzzle or craft, gardening, a soak in the tub, or a game of computer solitaire. Young children, whether the caregivers' or grandchildren, provided positive motivation during the days. Caregivers rationalized that a positive break was almost as helpful as a rest. One caregiver described the difference that a regular massage appointment at home made for herself...

*"We were getting massages, quite regular, ... just having that one night of relaxation, that massage thing, you know, just sort of brings your body back a bit."*

The overwhelmingly positive outlook of caregivers was epitomized by a caregiver who viewed the work of caregiving as her current exercise routine in place of time at the gym. In this way she valued running back and forth in the household to meet the patient's needs...

*"I don't go on the treadmill like I used to ...or swim laps in the pool ... so I'm compensating by, if he wants something, I'm there, you know running back and forth through the apartment..."*

Caregivers intentionally compensated for their diminished memory and concentration in various ways. A common strategy was described by this female caregiver...

*"My journal is my thinker...I write everything down, my dates, my appointments, whatever I have to do... for instance she is on a [pain medication] patch and I write down every third day...patch to put on her... things like that that I have to remember."*

Caregivers took control and minimized interruptions to their schedule by using an answering machine, limiting visits, or by communicating in group emails at a convenient time for themselves. Throughout the caregivers' narratives, there was also a definite

sense that family members drew strength from sharing the caregiving role with another like-minded family member.

***Category II: Getting Through the Restless Night***

Similar to the variety of strategies employed during the long days, caregivers tried diverse methods of promoting their sleep and rest through the night. This section summarizes the strategies described by the family caregivers interviewed in this study.

Family members shared similar perspectives regarding the decision-making process surrounding use of sleep medications. Two of the thirteen caregivers utilized prescription sedatives. They described its benefit as helping them overcome their ‘busy mind’ that plagued their ability to fall asleep at bedtime...

*“I do have to take a sleeping pill, you know half a Trazadone does it, then I don’t have that problem of my mind not shutting down, I’m able to go to sleep. It works for the first part of the night, but once she gets up, that might be it for the night.”*

*“In the last bit...I didn’t sleep well at all. I’d go to bed and your mind is, you know, it just doesn’t relax. Um, so, my doctor had given me some minor dose sleeping pills, so what I would do just so I could have a bit of sleep, maybe two days in a row, I would take half of one, and that was at the beginning, and now I can’t even sleep with that. So I take the full one when I go home to sleep... but when I’m here [in patient’s home], I don’t...because I’ve got to be sure I’m up and can hear things...just wanna be sure...that I’m able to hear [the patient] or the person that is looking after her.”*

Other caregivers described their hesitancy in using medication because they worried that they wouldn’t hear the patient if help was required. The caregivers also worried about whether the medication would inhibit their ability and readiness for caregiving in the night. The following narrative expresses this common sentiment shared by many of this study’s caregivers...

*“No [I would not use sleep medication], because, I’m concerned about it and [the patient], that if I take something then what if he’s in distress and needs me, then how am I going to be there for him, if I’m like a zombie.”*

In lieu of medications, caregivers tried various ways to promote bedtime sleep onset. Strategies included regular bedtime routines, or watching television, reading a book, listening to music or having a warm bath to unwind and promote relaxation...

*“Sometimes I watch TV but as a rule I read and just lie in bed quietly ...I pray...I don't pray for things, but I thank for things, because there is so much to be thankful for. ...If I think I am going to have a hard time getting to sleep or I am having a hard time – I fill the tub up with hot water and I soak in the tub until I am totally relaxed. Then I get up and go directly to my bed and drift off. It seems to help.”*

While most found a wide range of relaxation techniques helpful, one participant found that vigorous exercise followed by reading or television helped to release the stress and decrease bedtime restlessness.

Family caregivers experimented with technology to optimize sleep. Small commercially sold devices called ‘Dr. H.,’ were used for muscle stimulation and relaxation at bedtime on tired and tense muscles. Cell phones and baby monitors were used as a connection between the patients and caregivers; this connection boosted their confidence that if they fell asleep the patients could make themselves heard. In most cases, waiting for the phone to ring or listening to the magnified sounds on the monitors served to disturb their sleep. The following narrative points out the complexity of wanting to hear the patient but not wanting to hear everything...

*“I didn't get that bad of a sleep last night...I put a fan on, to drowned out any little noises, that keep me awake, I still hear them but I don't feel I have to get up, but I do need to, you know to block out, cause otherwise I'll hear everything, and then I won't sleep at all. I can still hear the monitor, but not every crackle.”*

This dilemma of needing to hear the patient, while trying to preserve some sleep by not hearing everything was demonstrated by the caregiver who resorted to wearing ear plugs

to block out the noise. Unfortunately, she could still sense every movement. Therefore, the ear plugs were deemed an ineffective solution.

Bedtime prayer was a common strategy used by the caregivers interviewed in this study. The routine prayers offered a vehicle to focus the mind at bedtime and promote peacefulness. Another method employed by one caregiver was a form of talk therapy where she would review what she was worrying about and rationalize or construct an answer for each...

*"...you know it took me a long time to really think it out, to know, I've done all that I can, there's nothing else we can do. We've done everything that the medical profession can do. It's out of everybody's hands, so we make the best of it and we continue, and then hopefully I fall back to sleep."*

This narrative also validates interventions related to advance planning. Caregivers voiced that when necessary arrangements were in place, it 'set their mind at ease.'

Families receiving night respite service recognized the difference that a little service could make in their ability to sleep and in sustaining their caregiving capacity...

*"We got a little help ... which relieved the pressure at the time, so then I was able to sleep better, because I also have to be involved during the day to give the medications... and, I wasn't the person in the bedroom [all night], it relieved me of a lot of pressure. It shared the responsibility and yeah, not being alone, I do have a very dread of being alone here [when patient dies]."*

Caregivers also linked past experience to their ability to manage with limited sleep. If they had raised teenage boys that kept them awake at night or had worked shift work as a nurse, these experiences were deemed helpful in their current adjustment to limited sleep quantity and quality.

While the family caregivers were able to identify the strategies they practiced to get through the days and nights, the majority of them struggled to identify what the health care system could do for them ...

*“I can’t answer that right now because, the way I feel and the way he is, we are managing right now and I am getting enough sleep ... if things change, then perhaps I could answer that.”*

The following is an insightful comment shared by a caregiver who had daily night respite in place ...

*“[The palliative care program] have done everything to make it as smooth and easy going as possible. I think it’s just, myself, if I have a problem now, it’s, it’s more about myself, it’s just me ... because I have so much confidence in these ladies that I, yeah, they’ve made it easier.”*

This comment touches on the complexity of sleep disturbance, the intrinsic component of the problem and the challenges that face health care professionals to offer meaningful and effective interventions. Sleep disturbance has a multitude of contributing factors and consequences with a cyclical nature – serving to exacerbate itself.

### ***Summary***

In this section, the salient qualitative findings have been presented under the major theme, *Sleeping with One Eye Open*, the sub-themes, *Factors Contributing to Family Caregiver’s Disturbed Sleep*, *Consequences of Family Caregiver’s Sleep Disturbance* and *Family Caregivers’ Strategies to Overcome Sleep Disturbance*, and the related categories and sub-categories. While the family caregivers were admittedly tired during the majority of the interviews, they willingly participated, admitted that they found the process helpful, and their narratives contained valuable information to understand their experience more fully. One family member summed it up by remarking, that it was good to have the opportunity to give ‘voice’ to the experience she was living.

### **Summary of the Quantitative Findings**

In this study, quantitative data was gathered to extend the understanding gained through the qualitative interview data, and answer the research questions in a more comprehensive manner. See Table 5.4 [p. 106] for a summary of the study's research questions and the measurement instruments utilized to obtain information on the sleep-related variables.

**Table 5.4 Research Questions With Corresponding Measurement Instruments and Variables**

Research Question	Instrument/Variables
1) How do family caregivers of community-dwelling advanced cancer patients describe their experience of sleep disturbance?	PSQI (Self-report): <ul style="list-style-type: none"> <li>- sleep quality</li> <li>- sleep latency</li> <li>- sleep duration (total sleep time)</li> <li>- sleep efficiency</li> <li>- degree of sleep disturbance</li> <li>- use of sleep medication</li> <li>- daytime dysfunction</li> </ul>
2) What is the objective portrayal of family caregivers' sleep disturbance as measured by actigraphy?	Actigraphy/Sleep Log: <ul style="list-style-type: none"> <li>- time in bed</li> <li>- total sleep time</li> <li>- sleep efficiency</li> <li>- wake time after sleep onset</li> <li>- sleep latency</li> <li>- sleep fragmentation</li> <li>- number and length of naps</li> </ul>
3) What factors do family caregivers identify as contributing to sleep disturbance?	PSQI and Actigraphy/Sleep Log: <ul style="list-style-type: none"> <li>-sleep latency</li> <li>-sleep fragmentation</li> </ul>
4) What consequences do family caregivers identify that sleep disturbance has on their ability to carry out their caregiving role?	No quantitative measurement
5) What consequences do family caregivers identify that sleep disturbance has on daily living and their own health and well-being?	ESS (self report): <ul style="list-style-type: none"> <li>- daytime sleepiness</li> </ul>
6) What do family caregivers identify as being helpful in managing the sleep disturbances that they experience?	No quantitative measurement

In this section, findings from the three sources of quantitative data will be presented. As summarized in Table 5.4, data was collected from the family caregiver

participants utilizing two self-report instruments, the Epworth Sleepiness Scale (ESS) and the Pittsburgh Sleep Quality Index (PSQI), as well as Actiwatch-64®'s (in conjunction with the sleep log) which collected actigraphy data over a 72-hour period.

### *Epworth Sleepiness Scale*

Total scores on ESS, which is designed to measure daytime sleepiness in adults, range from 0 - 24. The family caregivers' mean score on the ESS was 8.7 (SD = 5.52) which closely coincided with the median score of 9.0. In Table 5.5, note the large range of scores in this small sample.

**Table 5.5 Epworth Sleepiness Scale Findings**

Mean	8.7
Median	9.0
Std. Deviation	5.5
Range	19.0
Minimum	0.0
Maximum	19.0
(Possible range)	(0.0-21.0)

According to the results of the ESS, five of the thirteen family caregivers (38.5%) had a score  $\geq 11$  which is indicative of excessive daytime sleepiness.

### *Pittsburgh Sleep Quality Index*

The PSQI, intended to measure sleep quality as well as identify good and bad sleepers, produces seven component scores (ranging from 0 - 3) and a total score (ranging from 0 - 21). The desired range for the seven component scores is 0 - 1, while a total score of  $\geq 5$  indicates moderate sleep problems in at least three sleep components, or

severe sleep problems in two areas. Table 5.6 summarizes the PSQI findings from this study.

**Table 5.6 Pittsburgh Sleep Quality Index Findings**

<b>PSQI Component</b>	<b>Total Sample N=13</b>
#1 Subjective Sleep Quality	Mean 1.46 Median 1.00 SD 0.78
#2 Sleep Latency	Mean 1.23 Median 1.00 SD 1.01
#3 Sleep Duration	Mean 2.00 Median 2.00 SD 0.81
#4 Habitual Sleep Efficiency	Mean 1.69 Median 2.00 SD 1.11
#5 Sleep Disturbance	Mean 1.62 Median 2.00 SD 0.65
#6 Use of Sleep Medication	Mean 0.69 Median 0.00 SD 1.32
#7 Daytime Dysfunction	Mean 1.38 Median 1.00 SD 0.77
Total Sleep Score	Mean 10.08 Median 11.00 SD 3.99 Min 5.00 Max 15.00
(Possible Total Sleep Score)	(0.00- 21.00)

Based on the PSQI findings, the mean scores for six of the seven components were beyond the desired range. The only component score which was in the 0 - 1 range ( $M = 0.69$ ) was Component #6 - Use of Sleep Medication. Only three of the thirteen participants used prescribed sleep medication, while the other ten scored zero on the 0 - 3 range (i.e. not using sleep medication). This accounts for the median value of zero for Component #6. The highest component score ( $M = 2.00$ ) was Component #3 - Sleep Duration (Total Sleep Time). The mean sleep duration estimated by the family caregivers was 5.31 hours of sleep per night. While PSQI Component #7 – Daytime Dysfunction demonstrated that five of the thirteen participants were beyond the desired range ( $\geq 2$ ), only two of these five participants overlapped with the five participants identified by ESS as having excessive daytime sleepiness. All thirteen participants in this study had a total sleep score  $\geq 5$ , indicative of moderate to severe sleep problems.

### *Actigraphy*

Twelve of the thirteen study participants agreed to wear an Actiwatch-64® for a 72-hour period. As noted earlier, one participant decided not to participate in the actigraphy component of data collection, citing that the “interview felt like a sufficient commitment at this busy time.” Of the twelve participants involved in the actigraphy component, one participant had an allergic reaction to the wrist strap which limited her involvement to a 24-hour period. Also the actigraphy data analysis for two participants was restricted to a 48-hour period, as the patients they were caring for died prior to the third night of data collection. All twelve participants recorded detailed sleep logs which were helpful in the analysis of the data. Refer to Table 5.7 [p. 110] for a summary of the actigraphy findings.

**Table 5.7 Summary of Actigraphy Findings**

<b>Actigraphy Variable</b>	<b>Actigraphy Sample: n=12 (Missing, n=1)</b>
#1 Total time in bed (hours)	Mean 7.82 SD 1.33
#2 Actual sleep per night (hours)	Mean 6.67 SD 1.14
#3 Sleep efficiency (%)	Mean 84.88 SD 7.37
#4 Time awake after sleep onset (minutes)	Mean 41.93 SD 21.78
#5 Sleep latency (minutes)	Mean 18.67 SD 21.95
#6 Movement/fragmentation index (#)	Mean 11.61 SD 3.25
#7 Number of naps per day	Mean 4.81 SD 3.66
#8 Total nap time per day (minutes)	Mean 69.56 SD 56.04
#9 Average length of nap (minutes)	Mean 16.11 SD 10.76
#10 Number of naps $\geq$ 20 minutes	Mean .81 SD .86

In Table 5.6, the actigraphy mean scores for the sleep parameters #2 to #7 do not represent desired values. Regarding actigraphy variable #2 -Actual Sleep Time (total sleep time), 66.7 % of the participants received less than seven hours of sleep per night (M = 6.67 hours; SD = 1.14; Range = 3.2 - 8.9 hours). The mean sleep efficiency (actigraphy variable # 3) was 84.88 %, with 33.3 % of the family caregivers exhibiting sleep efficiency less than the desired minimum of 85% for adults. It is important to note that sleep efficiency is based on the scores for Actual Sleep Time and the Total Time in Bed. Caregivers may have a high efficiency score even if they are only in bed for four hours but are able to sleep for the complete, although, limited time period.

The sleep latency findings ( $M = 22.46$ ) demonstrated a delay in sleep onset similar to and indicative of insomnia in healthy adults ( $> 15$  minutes to fall asleep), as the desired range is 5 - 10 minutes (Lee, 2003). In addition, family caregivers were awake an average of 41.93 minutes per night after falling asleep ( $SD = 21.78$ ). This value is significant given that they are already sleeping less than the desired minimum of 7 hours per night.

Great variability was seen in the movement/fragmentation index (actigraphy variable #6) which ranged from 4 to 39 sleep interruptions per night, yet the mean and median values were closely related ( $M = 11.61$ ;  $Md = 10.32$ ;  $SD = 3.25$ ). In the caregivers' sleep logs these interruptions were attributed to: assisting the patients with care (e.g., most frequently toileting); administering medication; monitoring the patient's restlessness; awakening due to the noise of the patient's activity; awakening due to noise on the baby monitor; awakening due to the noise created by the night-time respite care worker; and the caregiver's own restlessness.

Actigraphy data revealed that it was not uncommon for the caregivers to have numerous micro naps, particularly in the evening hours, as evidenced by the number of naps captured per day ( $M = 4.81$ ). However, the mean number of naps greater than 20 minutes in length was only 0.81 (i.e., less than one per day). As noted in Chapter 2 [p. 12] the desired minimum length of nap to be restorative is 20 - 30 minutes (Kryger et al., 2005). A closer look at the actigraphy data reveals that nine of the thirteen participants had one nap ( $\geq 20$  minutes) during the three-day study period and only three of the thirteen participants had at least one nap ( $\geq 20$  minutes) per day for the three-day study period.

### *Correlations*

Bivariate correlational analysis using Spearman's rho correlation coefficient ( $r$ ) was conducted to examine relationships between the various demographic, sleep, and daytime sleepiness variables. For example, the patients' Palliative Performance Scale (PPS) scores were correlated with actigraphy findings to explore how the patients' functional status may affect the various caregivers' sleep variables. Only the significant correlations will be presented. A negative correlation ( $r = -0.903; < .01$ ) was discovered between the patients' PPS scores and the caregiver's actigraphy sleep latency findings (Variable #5). This indicates that as the patients' functional status score decreased (0% = death), the caregivers' time to fall asleep increased. Similarly, a negative correlation ( $r = -0.842; < .01$ ) existed between the patients' PPS scores and the caregivers' actigraphy movement/fragmentation index (Variable #6). In other words, as the patients' functional status declined, the caregivers' movement/fragmentation index increased.

### *Summary of Quantitative Findings*

Many interesting findings have emerged from the quantitative data. The ESS results demonstrated that five of the thirteen participants had excessive daytime sleepiness. All thirteen participants in this study had a PSQI total sleep score  $\geq 5$ , indicative of moderate to severe sleep problems. While all caregivers who participated in the actigraphy component of the study received less than the ideal 7 - 8 hours of sleep per night, all the caregivers perceived and estimated (PSQI self-report) that they had slept less than the actigraphy data illustrated.

### Summary

The purpose of this exploratory descriptive study was to better understand the concept of sleep disturbance in family caregivers of advanced cancer patients living in the community. This chapter presented demographic profiles summarizing characteristics for the thirteen study participants and their care-recipients. Findings which emerged through analysis of the qualitative and quantitative data sets were summarized and presented.

The overarching theme of ‘Sleeping with One Eye Open’ and the nature of this type of sleep described by the caregivers, was woven throughout the 13 narrative transcripts. The emerging sub-themes, contributing factors of disturbed sleep, consequences of disturbed sleep, and caregiver strategies to overcome disturbed sleep, provide a richer understanding of the family caregivers’ experience.

The small sample size limited the degree of statistical analysis, but interesting findings emerged from the quantitative data nonetheless. The ESS results demonstrated that five of the thirteen participants suffered from excessive daytime sleepiness, while all thirteen participants in this study had PSQI total sleep scores indicative of moderate to severe sleep problems. While the caregivers who participated in the actigraphy component of the study received less than the ideal 7-8 hours of sleep per night, they also perceived that they slept less than the actigraphy data illustrated. In Chapter #6, the findings will be explored and discussed further in the context of existing literature.

## CHAPTER SIX

### DISCUSSION AND CONCLUSIONS

#### **Introduction**

The purpose of this study was to explore and describe sleep disturbance in family caregivers of advanced cancer patients living in the community. This chapter will discuss the prominent findings of this study in the context of the current literature. Triangulation of the findings from the various data sources will be integrated throughout. The theoretical perspectives will be revisited to contemplate their suitability and effectiveness now that the study has been executed. Limitations of the study and recommendations for the future will conclude this final chapter.

#### **Discussion of Prominent Findings**

The value of any research study is derived from its relationship to and extension of previous findings. Hence, research gains its significance from the context within which it is placed (McEwen & Wills, 2002). Qualitative and quantitative findings from this study will be discussed in light of the current literature, with consideration given to how the findings from the two realms relate and inform each other.

#### ***Major Theme: Sleeping with One Eye Open***

As defined in Chapter Five, the overarching theme, Sleeping with One Eye Open, refers to the nature of sleep disturbance as experienced and described by the family caregivers. In the published literature, family caregivers describe this phenomenon in varying ways. Sleeping lightly due to the sense of being on duty day and night; listening for calls of help; or being aware of a wandering or restless family member, were reported in research involving the family caregivers of patients with Alzheimer's Disease

(Brummett, Babyak, & Siegler, 2006). Similarly, the caregivers of patients with Parkinson's Disease reported light and fragmented sleep resulting from the responsibility of providing round-the-clock care (Happe & Berger, 2002). Carter (2002) conveys this sense of family caregivers being on-call during the night as well as the day, ready to meet the 24-hour needs of advanced cancer patients. Many caregiver studies have described this type of night-time vigilance (Flaskerud & Tabora, 1998; Flaskerud et al., 2000; Knop et al., 1998). Other family members providing care at home reported difficulty sleeping as 'being half asleep' and vigilant of the person with AIDS, who was frequently up in the night with wandering behavior or discomfort from disease-related pain (Flaskerud et al., 2000, p.127).

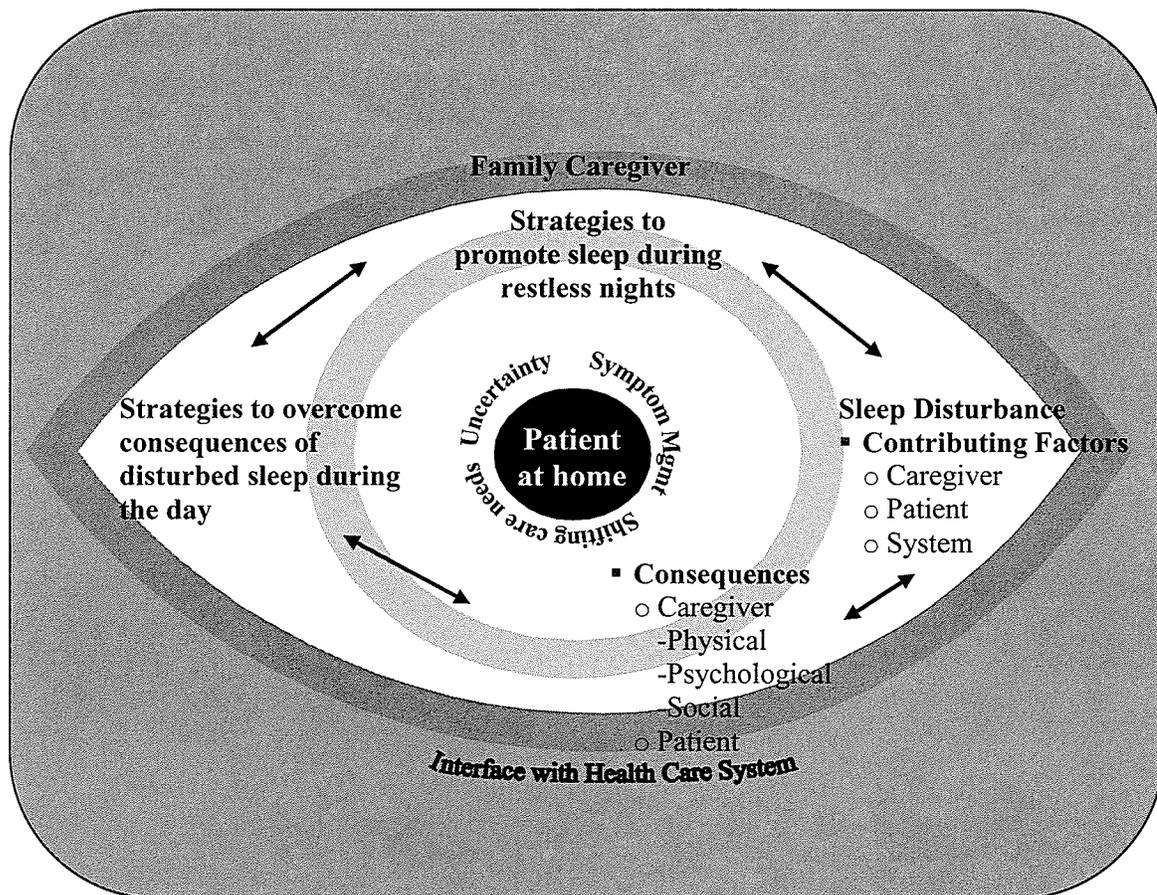
Sleeping with One Eye Open symbolizes what is known as vigilant sleep. In the Oxford Dictionary, vigil is defined as "keeping awake during the time usually given to sleep, especially to keep watch or pray" (Allen, 1990, p. 1369); while vigilant is defined as "watchful against danger or difficulty" (1990, p. 1369). Family caregivers providing end-stage cancer care at home remain vigilant day and night towards their dying loved ones, bearing witness to their changing health status, and their changing physical and emotional care needs. The caregivers in the current study concurred that they were on 24-hour call or constant stand-by in case their loved one should need emotional comfort or physical assistance.

The thirteen caregivers' sleep was consequently experienced as 'light' as opposed to deep and restorative. The caregivers repeatedly described their sleep using the common colloquialism, 'sleeping with one eye open'. As qualitative themes emerge true to participants' narratives, these words serve to best describe the essence of their current

sleep experience and the overarching theme of these study findings. The nature of this vigilant 'Sleeping with One Eye Open' is repeatedly described in published literature as fragmented and increased time awake throughout the nights (WASO), and early morning awakening (Carter & Chang, 2000; Carter, 2002; Carter, 2003).

The complexity of this theme is best understood by exploring the sub-themes that emerge. Caregivers readily identified the numerous factors that contributed to this type of sleep disturbance. They also recognized the consequences of not acquiring their usual quantity and/or quality of sleep while 'sleeping with one eye open.' When caregivers were asked to share their suggestions on how formal health care providers could best help them in promoting their rest and sleep, they identified various strategies they had tried to promote their sleep. They also identified strategies for surviving the days after restless nights. Caregivers were less able to recommend how health care providers might help them. However, by exploring further the salient sub-themes, categories and sub-categories in the caregiver narratives, a better understanding of their sleep disturbance is gained and the foundation for future practice and research created. For a visual depiction of the sub-themes and categories which emerged see Figure 6.1 – Sleeping with One Eye Open [p.117].

**Figure 6.1 - Sleeping with One Eye Open**  
**The Nature of Sleep Disturbance in Family Caregivers of Advanced Cancer Patients**



### ***Sub-Theme: Factors Contributing to Family Caregiver's Sleep Disturbance***

As noted earlier, the family caregivers were able to articulate many factors that contributed to their disturbed sleep. The resulting sub-theme which emerged from the transcripts refers to those people, places, thoughts, and events identified by caregivers that singly or collectively contribute to a change in their sleep quantity and quality. As summarized by Berger and colleagues (2005), a multitude of factors, including personal, environmental, lifestyle, psychosocial, physical, disease and treatment-related factors may interfere with normal sleep for the cancer patients and their caregivers. It is important to recognize at the onset of this discussion that these factors change from day-to-day, even hour-to-hour for these patients and families (Hileman, 1992; Vena et al., 2004). To increase clarity, this sub-theme has been divided into the categories; Caregiver-Related Factors, Patient-Related Factors and Health Care System-Related Factors.

#### ***Category I: Caregiver-Related Factors***

The first category encompasses the various factors related directly to the caregiver, and is further divided into the sub-categories of psychological factors, physical/environmental factors, social factors, and personal beliefs regarding sleep debt. Carter's research also found that cancer caregivers' sleep quality is affected by physical, emotional and social factors (2006).

**Psychological factors.** Research findings indicate that caring for a family member with advanced cancer can be psychologically demanding and stressful (Mangan et al., 2003; Scott, Whyler & Grant, 2001; Stajduhar, 2003). The major risk factor for disturbed sleep in healthy adults is stressful life events, particularly when emotions and recurring thoughts prevail (Lee, 2003). Therefore, many of the factors discussed

throughout this sub-theme are those identified by the thirteen family caregivers that may contribute to their increased stress and therefore, their inability to sleep. Each caregiver in the current study shared numerous thoughts, worries, feelings and descriptions of the constant decision - making that consumed their minds and plagued their ability to sleep. Caregivers described their minds as 'working overtime,' keeping them awake at bedtime, during the night or early in the morning. This heightened emotional stress has been described by other researchers as feeling overwhelmed and worried about one's ability to cope (Scott et al., 2001) and feeling tense and restless (Carter, 2002), all contributing to the cancer caregivers' inability to sleep.

All caregivers in the current study worried first and foremost about the comfort and safety of the patients in their care. Therefore concerns regarding the patients' changing functional status and care needs, fluctuating symptoms and their management, and whether alternate placement may be required, were the cause of consternation and the ongoing decision-making experienced by the caregivers. 'Mental-filing' was a descriptor used by one of the study participants to describe the brain activity that kept her awake at night. These family perspectives were consistent with those of Stajduhar (2003) who interviewed 57 family caregivers in a Canadian study for the purpose of describing the family members' experiences providing home-based palliative care. She reported that family caregivers are constantly asked to be involved in decisions regarding the patient's care, change in medication regimes for symptom management, and the best place of care. This constant decision-making and worry whether the family would be able to continue to provide the necessary care at home, were commonly linked with the fragmented sleep of caregiving (2003).

Decisions related to advance care planning arose in this study's interviews as another source of stress and night-time worry. Planning involved decisions related to resuscitation orders, preparation for a home death, funeral arrangements, and financial affairs. One spouse described how the details of her husband's obituary ran repeatedly through her head together with the worry of whether she could write something which would rightfully honor his life. Families in the current study who had outstanding questions or arrangements at the point that the patient could no longer communicate in a meaningful way, voiced the angst and sleeplessness associated with making the right decisions.

A synthesis of published findings regarding family decision-making at the end-of-life documented the high levels of stress and the great moral, emotional and cognitive demands on family surrogates in these situations (Meeker & Jezewski, 2005). The authors stressed the need for quality communication and exchange of information between the patient, family and health care professionals to facilitate timely and optimal decision-making. Teno and colleagues' research (2007), which examined the role of advance care planning and directives by interviewing bereaved family members, reiterated the importance of these ongoing conversations. They found that advanced care planning is associated with greater use of palliative care services, the caregivers' increased satisfaction with health care professionals' communication, and a trend towards improved perception of quality of end-of-life care. Carter (2005) discovered that these worries continued to disturb sleep into bereavement as family caregivers described having repeated nightmares about having made the wrong decisions on behalf of the patient.

The participants in the current study described the emotional roller-coaster of caring for a dying relative at home. Feelings of thankfulness, humor and love, ebbed and flowed with feelings of sadness, anger, guilt and grief. They indicated that these various emotional reactions contributed to their ability to sleep or not. Hudson (2004) has documented this mixture of emotions, with negative feelings amid the many positive aspects and feelings associated with providing palliative home care. Family members voiced a range of emotions from fear of going to sleep to frustration at not being able to fall asleep (Hudson, 2004). Certainly depression has been repeatedly identified as a factor associated with difficulty sleeping in the advanced cancer caregiver population (Carter, 2002; Carter & Acton, 2006; Carter & Chang, 2000) as well as in caregivers of patients with Alzheimer's Disease (Brummet et al., 2006) and Parkinson's Disease (Pal et al., 2004). Current participant narratives alluded to the feelings of depression which they experienced while caring for their dying loved one, particularly if the period of caregiving had extended (i.e., longer three months).

Guilt was commonly associated with caregivers' needs to have time away from the home, time to rest, and time to obtain adequate sleep. As reported elsewhere (Aranda & Hayman-White, 2001; Steele & Fitch, 1996), caregivers were well aware of the importance of self care and rest, yet these were accompanied by feelings of guilt related to abandoning the patients' needs. Caregivers also spoke of the vicious cycle: inadequate sleep leads to feelings of irritability, resentment and anger, which in turn translates into guilt, and then the caregivers regret these feelings towards the patient, and so on. This roller-coaster of emotions has also been documented by Carter (2002), based on her interviews with caregivers of advanced cancer patients. Caregivers also indicated that

worries regarding their employment and financial status troubled them at night. These concerns will be addressed under Social Factors [p. 124].

A huge emotional component of providing end-of-life care is referred to as anticipatory grief. Countless losses are associated with end-of-life care – physical, relational and symbolic (Kissane, 2004). The anticipatory grief expressed by the family caregivers in this study was related to current as well as future losses as previously documented by Kissane. The family caregivers here identified these losses, beginning with the patient's cancer diagnosis. They then described subsequent losses such as the recurrence of disease, decision to cease treatments, loss of functional status, loss of ability to communicate, loss of sexual intimacy, and the realization that death was inevitable. These losses are consistent with those documented by other researchers in the field; Hudson (2004) and Jo and colleagues (2007) reported the emotional strain and loss associated with watching loved ones deteriorate, adjusting to the losses in their lives, and missing the usual personalities of their loved ones. Lev and McCorkle (1998) asserted that these images and losses were the most difficult part of palliative caregiving. In this study, each of these losses and grief reactions set the caregivers' minds in motion, and therefore coincided with many of the events across the illness trajectory which they also identified as contributing to sleep disturbance. Their losses also coincide with previous research related to the illness spectrum (Duke, 1998). Carter (2006) reported that grief and bereavement work interferes with the caregiver's ability to gain adequate sleep, while conversely, inadequate sleep may interfere with the work of grief, prior to and following the death of a loved one.

**Physical/environmental factors.** Various physical and environmental factors contribute to disturbed sleep at home. When advanced cancer patients are cared for at home, their sleeping arrangements frequently change as their functional level and care needs change. These changes may include a shift to a different bed, to a different room, and to no longer sleeping with their partner. It is not uncommon for a central living area of the home to be converted to a hospital-at-home, complete with a hospital bed, alternating pressure mattress, oxygen concentrators and other necessary equipment. These changes contribute to a sense of unfamiliarity, as well as an alteration in noise and light levels in the own home environment. Also, many visitors and/or health care providers come and go to provide psychosocial support or round-the-clock physical care. The environmental changes and revolving door associated with in-home palliative care are well-documented (Angus, Kontos, Dyck, McKeever, & Poland, 2005; Efrainsson, Hoglund, & Sandman, 2001; Stajduhar, 2002). Stajduhar's (2003) findings refer to the hospital-like home setting created in the final months of palliative care provision with the family-come-nurse-caregiver assuming the 24-hour responsibility. Stajduhar reported that the majority of these changes are made with the patient in mind as opposed to their effects on the caregiver.

Family caregivers interviewed in this study described how they had to adjust to sleeping apart from their spouse, in a new location, on a different bed or with new noise and light levels. Family members who had accepted day or night respite service commented on the need to adjust to the presence of strange voices and footsteps in their home. Family members who were living away from home while caregiving had to adapt to sleeping in a completely new environment. It was not uncommon for the couch to

become their new sleeping location. Multiple study participants used the term 'couch night' when describing their assessment of how much assistance the patient may require on a given night. If they deemed frequent assistance, supervision or companionship would be needed, caregivers decided to spend the night on the couch to be close at hand. The expression 'couch night' did not surface in any of the research reviewed by researcher.

In the current study, the use of technology was another environmental factor which emerged as a contributing factor to disturbed sleep. It became evident to the researcher that the use of technology, intended to bring peace of mind to the caregiver, soon became a double-edged sword. For family members returning to their own home for a good night's sleep, keeping a telephone close at hand maintained their connection to the caregiving situation. The phone, intended as assurance, became the dreaded companion, as they laid awake worrying that it would ring. In-home baby monitors, were also observed to be a mixed blessing. Like telephones, monitors were utilized to provide a sense of connection to the patient while the caregiver slept in a different room or part of the home. These sensitive machines transferred the sound of every breath, cough and rustle from the patient's bedside to the caregiver's bedside. As a result, the caregivers described being aroused throughout the night by these sounds. It is doubtful that these findings are unique, but previous documentation was not found. However, environmental and physical changes described in this study as contributing to the family caregivers' sleep disturbance have been recognized in the literature to increase sleep onset latency and arousals during the night with associated fragmentation and WASO (Lee, 2003).

**Social Factors.** The most common social factors which contributed to poor sleep identified by the family caregivers in the current study were employment status, family dynamics, and change in family roles. Eight of the thirteen participants were still employed, however six of the eight were either working reduced hours, on sick-leave or on disability leave. One participant had just returned to full-time work after a period of sick-leave due to 'burn-out' and exhaustion. The caregivers' stories reflected the challenges inherent in balancing career and caregiving roles, with the quality and quantity of sleep tipping the balance. Caregivers indicated that reducing their work schedules or taking time off work, was helpful in sustaining themselves as caregivers. These findings are consistent with other studies that have identified financial difficulties or balancing work with caregiving as added stressors for family members (Jo et al., 2007; Mangan et al., 2003; Stajduhar, 2003; Scott et al., 2001; Williams, Crooks, Stajduhar, et al., 2006). In contrast, two caregivers in this study valued time at work as a break from caregiving even though they were very tired, trying to do both.

The thirteen caregivers in the current study described family dynamics that contributed to their sleep disturbance. A number of participants described recent family deaths and other major illnesses in the family which caused them additional stress and worry. They also referred to the stress caused by un-helpful family members, which caused some caregivers to feel exploited. Previous research found that 30 % of family caregivers of dying cancer patients experienced family-related stress based on family relationships, lack of assistance with care and the needs of other family members (Hudson, 2004). Other researchers have suggested that young family caregivers especially experience increased stress in their caregiving roles (Scott et al., 2001). These

previous findings are congruent with the findings in this study as the younger caregivers attempted to juggle care of their own children as well as care for the patients and work. Mangan and colleagues (2003) described the juggling act of balancing work and caregiving, as well as the challenges of adopting new roles and responsibilities. Assuming additional roles, which in turn created more work and stress, was noted throughout this study. The caregivers described assuming all the household and yard chores, shopping, cooking and running errands, in addition to caregiving. As noted in Chapter Five, one caregiver, in addition to her own employment, housework, and caregiving, took on the role of carpenter and general contractor to finish her husband's basement renovation project. She even cared for the security dog at his local business.

The stress of social isolation was also noted. If the patient was no longer able to go out or socialize, family caregivers felt this as their own loss and often reported feeling housebound. Scott et al. (2001) and Hudson (2004) described how advanced cancer caregivers become housebound resulting in social isolation, which in turn contributed to other problems. Caregivers in the current study described the vicious cycle that can develop around sleep disturbance and social isolation. The more tired caregivers became, the less energy they had to initiate or maintain social contact outside the home. This in turn, contributed to depressed mood and sleep disturbance. Carter (2000, 2002, 2003) has described these same scenarios in her studies that focused on the relationship between caregiver sleep disturbance and depression.

The narratives of these thirteen caregivers which portrayed the social factors affecting sleep were incredibly consistent with the findings obtained through focus groups with caregivers (N = 42) of terminally ill seniors, HIV/AIDS and cancer patients

(Cain, Maclean, & Sellick, 2004). Exemplars provided by these authors illustrated the same sentiments regarding the difficulties of obtaining sufficient sleep to balance work and caregiving, the financial drain of reduced work time, difficult relationships within families which contribute to the stress of caregiving, and the inevitable social isolation experienced due to lack of time, energy, and respite.

**Beliefs about sleep debt.** A good night's sleep is often taken for granted and thought to be easily regained at a later date without significant consequences (Lee, 2003). The caregivers in the current study commonly referred to 'making do' with a limited amount of sleep or managing through the week if they had the opportunity for one good night's sleep on the weekend. Carter (2002) also found that caregivers were willing to sacrifice themselves for the interim period of caregiving, and that even 'one good night's sleep', would help sustain them.

### ***Category II: Patient-Related Factors***

The second category contains all the patient-related factors which the caregivers in the current study identified as contributing to their sleep disturbance. It is well-known in the health care community that patients with advanced cancer have complex needs. A study which examined the problems and care needs experienced by advanced cancer patients living at home (N = 90), developed a topic list of ninety potential problems (Osse, Vernooij-Dassen, Schade, & Grol, 2005). A multitude of physical, psychosocial, and spiritual problems were experienced by these patients. Individuals with advanced cancer at the end of life often require 24-hour assistance for personal care and medication administration (Carter, 2002; Kristjanson et al., 2004). The majority of palliative cancer patients are also prone to disturbed sleep patterns themselves (Davidson et al., 2002; Lee

et al., 2004; Sela et al., 2005). Therefore it is not surprising that patient-related factors surfaced as antecedents to caregiver sleep disturbance. To increase the clarity of discussion, the category of patient-related factors is organized into four sub-categories: uncontrolled symptoms, decline in functional status, disruption of the sleep/wake cycle, and the patients' reluctance to accept outside help.

**Uncontrolled symptoms.** A common phrase shared by family caregivers in the current study was 'if the patient sleeps, I sleep.' Family caregivers shared experiences which revealed how inadequate symptom management impacts on the patients' and families' ability to sleep. Hugel et al. (2004) reported that 70% of patients entering a hospice setting had insomnia, and uncontrolled physical symptoms was the cause in 60% of the cases. Hugel and colleagues reported that pain, urinary frequency, and dyspnea were the most common causes of patients' sleep disturbance, while Kristjanson et al. (2004) cited patients' restlessness/agitation, anxiety, incontinence, and complex care needs as the most common causes for caregiver sleep disturbance. Aranda and Hayman-White also reported that pain was the most common symptom demanding caregiving and was also frequently inadequately managed (Aranda & Hayman-White, 2002). In the current study, patients' pain, restlessness, confusion, and incontinence were the predominant symptoms that interfered with patients' and caregivers' ability to sleep. Throughout the caregiver interviews, the wisdom of published findings was reinforced. In other words, the extent and management of the patients' physical symptoms as well as psychosocial-spiritual concerns will influence the sleep quality and quantity of both the patient and caregiver (Berger et al., 2005).

If symptoms were poorly controlled, the caregivers in the current study echoed the sentiments of caregivers in other studies (Cain et al., 2004; Carter, 2002), confessing that if they were extremely tired, particularly in the midst of poor symptom control and suffering, they prayed that the patient would die.

**Decline in functional status.** In this study, the Palliative Performance Scale (PPS) (Anderson et al., 1996) was used to determine the status of the patient at the time of the caregiver interviews. This functional scale assesses ambulation (from full to totally in bed), level of consciousness (from full to coma), and dietary intake (normal intake to nothing orally). The patient is rated from full functioning (100%) on a continuum to death (0%). The PPS for the patients in this study ranged from 10 - 50% with a mean score of 39.2%. At the time of analysis, eight of the thirteen patients had died. It was evident through the caregivers' narratives that as the functional status of the patient declined, the caregivers' sleep was increasingly interrupted to assist with toileting, repositioning, or to provide supervision and companionship throughout the night. The caregivers' sleep logs illustrated extensive variability from night to night in the number of sleep interruptions and the types of care provided. It is important to mention that some caregivers reported that they were still sleeping fairly well. The caregivers attributed this to the patients' continued ability to transfer independently to a bedside commode and reposition themselves in bed. This was in contrast to those patients who required intermittent assistance and supervision due to restlessness, confusion, toileting, change of clothing due to incontinence, and assistance back to bed and repositioning. These findings are like those reported by a qualitative study by Carter (2002). She found that the demands for night-time caregiving were dependent on the degree of restlessness and the

need for assistance with toileting. Kristjanson et al. (2004) found that declining health and increasing needs of the patient dictated timely access to respite care.

**Disruption of sleep/wake cycle.** Many participants in the current study described how the patients' sleep/wake patterns were altered. Palliative care of cancer patients typically involves analgesia and other pharmacological interventions to control the various symptoms. These medications may cause daytime drowsiness. Also, as the patients' PPS score declines, they spend more time lying down or in bed. The combination of these two factors may result in increased daytime sleep and increased night-time wakefulness. Another potential cause for sleep/wake disruption of the patients' sleep cycle described by family members, stemmed from the quality of home care. If home care attendants allowed the patients to sleep for extended time periods during respite while the caregiver was out of the home, the patient may be unable to sleep when the caregiver returns and is ready for bed. The caregivers described the challenge of obtaining enough sleep if the caregiver and patient developed opposing sleep cycles. Cain and colleagues (2003) reported similar frustrations and challenges of family caregivers.

**Reluctance to accept outside help.** Cain et al.'s (2003) findings also articulated the obstacles to caregivers' sleep and rest caused by patients who refused respite services. These researchers reported that paid home care workers and unpaid hospice volunteers were often viewed by the patient as an unwanted intrusion or a threat to their privacy. In the current study, family caregivers described how the care-recipients did not want strangers sitting and watching them. The caregivers also reported that the patients felt they did not have the energy to familiarize service providers to their home or maintain a dialogue with them. These shared sentiments were echoed in the study by Cain et al., as

well as the challenge of balancing the wishes of the patient with the caregivers' need for respite.

### ***Category III: Health Care System-Related Factors***

The third category is comprised of factors associated with the interface between the health care system and the family caregivers, which have the potential to modulate and/or exacerbate the caregivers' sleep disturbance. This category is further divided into the sub-categories of assessment, knowledge/acceptance of services, and quality of care.

The majority of caregivers in the current study indicated that they would hesitate to report sleep problems to health care providers, and few caregivers had received inquiries regarding their sleep status. This unfortunate pattern is consistent with reports from other studies (Bramwell et al., 1995; Hudson, 2004). Previous research has found that caregivers are often hesitant to raise concerns regarding their own health and well-being as they place the needs of the patient ahead of their own. They may not recognize the importance or the impact of certain problems such as altered sleep, and they do not want to detract from the patients' complex problems, care needs and questions (Hudson, 2004). Caregivers do not want to be judged as inadequate, and they perceived sleep disturbance as an expected outcome of caregiving. They may believe that nothing can be done to improve their situation (Ramirez, Addington-Hall & Richards, 1998).

Three of the caregivers in the current study discussed their sleep problems with their physician and sleep medication was prescribed in two of the three cases. Otherwise, most of the caregivers indicated that *if* they talked to anyone, it would be the palliative care visiting nurse or coordinator. This choice was based on the hope and belief that the coordinator or nurse would be aware of and able to plan for available services. Previous

research has suggested that caregivers with a history of health problems may have a greater risk for psychological morbidity during caregiving, but are also more likely to recognize and report the problem of poor sleep and its consequences (Jepson, McCorkle, Adler, Nuamah, & Lusk, 1999). This is consistent with caregivers in the current study who had sought medical advice due to past health problems.

Mangan et al. (2003) reported that caregivers wished to be reminded of their own needs during the intensity of caring for a dying relative. The caregivers in this study had not taken time to consider their sleep changes or the consequences of inadequate rest, until the interview with the researcher. This reinforces the need for health professionals to assess and teach family members about the importance of sleep.

Aranda and Hayman-White (2001) found that in home-based palliative care, only up to one hour of professional care was received per day, thereby leaving the majority of the responsibility with the family. While the majority of families in this study reported that they were aware of the coordinator of the patients' home care services and appreciated the support available, they also indicated the amount, timing, and clarity of the information could be improved. The families indicated that they needed to be made aware of the scope of practice of the home care workers, the care they could provide and how families could provide feedback regarding the service.

When respite services were provided, the participants in the study emphasized the importance of consistency in the workers coming into their homes. Other studies report similar findings in that family members are constantly training new personnel which negated their ability to sleep or have a break (Cain et al., 2003; Stajduhar, 2003; Williams, 1999). The family caregivers in this study expressed great concern about home

care workers who were not suitable to provide in-home care and described how they felt they could not trust the night-time care of their loved one to them. Even though the family caregivers were unable to sleep when the worker was in the home, they hesitated to report problems to the managers, as they feared all the in-home services would be revoked. These family narratives confirmed the significance of quality of outside care. They judged the quality of care based on their ability to continue to accept the service provided, and the improvement of the caregivers' sleep quality and quantity.

***Sub-Theme: Consequences of Family Caregiver's Sleep Disturbance***

The family caregivers in this study identified many consequences resulting from the changes in their sleep quality and quantity. These consequences are organized into four categories: the effects on the caregiver's physical health; the changes in the caregiver's emotional status and cognitive functioning; the impact on the caregiver's social status (including interactions with others and job performance if employed beyond the caregiving role); and, the consequences of the family caregiver's sleep disturbance on the care-recipient. The consequences of poor sleep are well-documented in the general sleep literature as well as in the caregiver literature reviewed in preparation for this study. The consequences identified by the family caregivers of advanced cancer patients in this study were consistent with those found in the literature.

***Category I: Physical Consequences for the Caregiver***

Jo, Brazil and Willison (2007) report that the most common physical strain of caregiving is tiredness and weariness, with caregivers longing for sleep. Likewise, in this study, caregivers described the tiredness and lack of energy that they experienced. Excessive daytime sleepiness is the most common result of poor or insufficient sleep

(Vena et al., 2004). These researchers also found that many people have limited insight into the nature and severity of daytime sleepiness and its effects on their daily lives. Excessive sleepiness and the associated psychomotor and cognitive changes, increases the risk of accident or injury (2004). This consequence was exemplified in the current study by the caregiver reports of falling asleep while driving. Aranda and Hayman-White (2001) reported that 69% of caregivers of advanced cancer patients receiving home-based service are fatigued. They also noted that this fatigue contributed to the caregivers' perception of decreased health and well-being. The study by Teel and Press (1999) demonstrated that providing informal home care extracts a significant health cost among older adults, as they assess their health less positively when compared to non-caregivers.

Fragmented or decreased sleep can result in physical health problems. Caregivers who are awakened involuntarily to provide patient care had a high mean score for fatigue as well as increased blood pressure scores (Tsukaski, Kido, Makimoto, et al., 2006). As described by the caregivers in this study, sleep disturbance frequently alters a person's normal exercise and dietary routine which contributes to either weight loss or gain (Lee, 2003). Poor sleep places the caregiver's health at risk, as it alters metabolism, changes endocrine function and decreases immunity which may result in new illnesses or exacerbates existing health problems (Lee, 2003; Spiegel, Leproult, & Van Cauter, 1999). It has also been reported that caregivers who feel highly stressed in their caregiving roles showed a 63% increase in mortality over a four-year period compared to non-caregivers or caregivers who do not report high levels of stress (Schulz & Beach, 1999).

Evidence also points to elderly caregivers being at higher risk for physical consequences of sleep disturbance (McKibbon et al., 2005; Wilcox & King, 1999), while

others report that younger family caregivers experience greater psychological consequences (Scott et al., 2001). The average age of family caregivers in this study was 58.5 years, with the two oldest caregivers (in their early seventies) reporting good health and high energy levels. However the two youngest caregivers ( $\leq 50$  years), disclosed the stress and challenges associated with trying to balance work, child-care, and patient-care responsibilities. Carter (2005) describes the possible long-term consequences for caregivers, with sleep loss causing chronic sleep/wake pattern alterations.

***Category II: Psychological/Psychomotor Consequences for the Caregiver***

Caregivers' in this study described many psychological changes they had experienced as a result of altered sleep quality and quantity, which included increased irritability, decreased patience, anger, feeling overwhelmed, feeling 'down' or as if they were 'going crazy.' These emotional reactions are common. Carter (2002) presented comparable narratives which articulated the irritability, anger, and impatience experienced by tired caregivers.

Caregivers' relate feelings of depression to poor sleep in this study. Similar caregiver sentiments have been reported by other authors (Jo, Brazil, & Lohfeld, 2007), such as, "you sort of get down sometimes when you're all alone and alone with your thoughts." Published work related to Alzheimer's Disease corroborates that altered sleep quantity and quality may be attributable to negative affect and diminished social interactions (Brummett et al., 2006). Carter's program of research has focused on the relationship between sleep disturbance and depression in the family caregivers of cancer patients (2000, 2002, 2003, 2005, 2006). Her studies have repeatedly shown that approximately 50% of caregivers who experience problems with overall sleep quality,

daytime dysfunction and sleep efficiency, have Centre for Epidemiological Studies – Depression (CES-D) scores  $\geq 16$ . These CES-D scores are indicative of risk to develop clinical depression.

In the general sleep community, it has been demonstrated that 80% of depressed patients have secondary sleep disturbance, while sleep disturbance can place a person at risk for developing depression (Roehrs, 2000). Due to her past history of clinical depression, a study participant worried about an increased risk of negative consequences from disturbed sleep. Currently nursing researchers in cancer care and sleep are exploring the relationship within symptom clusters which include sleep and depression (Beck, Dudley, & Barsevick, 2005; Dodd, Miaskowski, & Paul, 2001; Payne, Piper, Rabinowitz, & Zimmerman, 2006).

The family caregivers in the current study were also quick to identify the psychomotor or cognitive changes associated with being tired. These changes included decreased memory, concentration, and ability to read and write. Similarly, Aranda and Hayman-White (2001) described the biggest consequence of caregivers' fatigue as being the decreased ability to think and concentrate. These were followed by decreased motivation, decreased mood, and decreased ability to perform necessary activities. Similar to the caregivers in this study, Carter (2005) shared caregiver narratives that depict the frustrations of walking into a room and forgetting why one was there.

Sleep disturbance in family caregivers may also impact their competence, confidence and satisfaction in the caregiving role (Aranda et al., 2001). Family caregivers in the current study discussed their concerns about whether they would be able to provide the necessary care if they did not sleep at night. As home care increases in complexity,

caregivers need to maintain their mental acuity and psychomotor and problem-solving skills in order to provide competent care. Certainly the medication administration errors reported by one caregiver in this study, illustrate the reality of these concerns. Caregiver exhaustion resulting from disturbed sleep may necessitate premature or unwanted institutionalization for the patient (Bramwell et al., 1995). This may be especially disturbing for family caregivers who made a commitment to care for a loved one in the community (Stajduhar, 2003).

### ***Category III: Social Consequences for the Caregiver***

The social costs of caregiving in general have been explored by numerous authors (Aoun et al., 2005; Deeken et al., 2003; Emanuel, Fairclough, Slutsman, & Emanuel, 2000; Fast & Keating, 2000; Haley, 2003). In this study, the caregivers shared stories that illuminated how sleep disturbance affected them socially. As alluded to earlier, the caregivers still employed beyond the home, recognized the impact that poor sleep was having on their job performance. Lee (1997) indicates that caregiver sleep status does not necessarily affect absenteeism but work performance. Some examples of diminished job performance shared by caregivers in this study include, falling asleep at their computer, decreased quality of written work, decreased interactions with others in the workplace, and the need to nap during work hours. Many of the caregivers in this study indicated that they could only manage being the primary caregiver to the dying relative if they reduced their hours of work or took advantage of sick leave. They felt they were not adequately rested nor did they have the required energy to maintain both roles.

The family caregivers in the current study indicated they did not have enough energy to maintain their usual social interactions with friends and families. They also

believed that sleep disturbance was altering their energy level and mood, which in turn, was having a negative influence on relationships with their immediate family members beyond the patient. For example if a daughter was caring for a parent, she felt her relationship with her own children or husband was affected. Cain and colleagues (2004) described this dual sense of responsibility which leaves caregivers feeling overwhelmed and inadequate at meeting the needs of the patient or other family members. Aranda and Hayman (2001) also reported that caregivers do not have the time or energy to invest in friendships or family relationships which only leads to further isolation.

Under the realm of social factors, health care professionals need to address the quality of life of the caregiver as well as the patient (Cohen, Leis, Kuhl, et al., 2006; Mangan et al., 2003). Carter (2006) reports that sleep duration and sleep efficiency are positively correlated with the caregiver's quality of life. In other words, the lower the sleep parameter scores, the lower the quality of life scores. The relationship between poor sleep and diminished quality of life has been described in the literature related to elderly caregivers (Wilcox & King, 1999), Alzheimer's Disease (Brummet et al., 2006) and Parkinson's Disease (Pal et al., 2004).

#### ***Category IV: Consequences for the Patient***

Closely intertwined with the sleep disturbance consequences for the caregivers are the consequences for the patients. It has been reported that caregivers' poor sleep affects the quality and feasibility of home care for the patients (Carter, 2002).

The changed effect of the family caregiver may potentially have a negative effect on the relationship between the caregiver and their loved one. Caregivers spoke of feeling guilty when they reacted to the patient in a manner which was different from their usual

pattern. Caregiver irritability, anger, and depression all may affect their interaction with the patient. In previous research it has been reported that the patient-caregiver relationship itself is also affected as the patient watches the caregiver become more and more tired (Mangan, 2003). This has a negative impact on the patient – he or she feels guilty and a burden to loved ones.

Any deficits such as poor sleep experienced by caregivers may inhibit their ability to provide good quality care (Pasacreta & McCorkle, 2000). The negative effect on quality and safety of the patients' care was noted by caregivers in this study. Caregivers worried about their competence with complex medication management in light of their forgetfulness and problems concentrating. As noted earlier, caregivers admitted to medication management errors which are a concerning negative consequence for the patient. They also described the inner personal struggle and lack of energy associated with responding to repeated calls for help at night. While caregivers were usually able to get up to provide the necessary care, at times exhaustion made this almost impossible. The caregivers in the study identified the potential consequences for the patient and themselves if they failed to respond quickly to the patients care needs in the night. These potential consequences included: the patient may take the wrong medications, the patient may fall, the patient may be incontinent which threatens self esteem and safety as well as creates more caregiver work such as changing clothing/bed linen and additional laundry, the patient may not be able to get back into bed comfortably, which further impedes the sleep of the patient and caregiver.

Another serious consequence of caregiver sleep disturbance and exhaustion is the premature institutionalization of the patient; this consequence was discussed by

caregivers in the current study and reported in the advanced cancer caregiver (Bramwell et al., 1995; Kristjanson et al., 2004), Alzheimer's Disease (Brummet et al., 2006; McKibbin et al., 2005), and Parkinson's Disease (Happe et al., 2002) literature. In a study of elderly caregivers of patients with cancer, dementia and Parkinson's Disease, Teel and Press (1999) reported that disturbed sleep negatively affected the caregiver-patient relationship and was the main predictor of institutionalization.

***Sub-Theme: Family Caregivers' Strategies to Overcome Sleep Disturbance***

Family caregivers in the current study were able to identify numerous strategies to overcome disturbed sleep. The sub-theme is divided into two categories: strategies used during the day to help caregivers physically and mentally get through the long days of caregiving, and strategies used to optimize sleep during the night while caregiving. Very limited intervention research has been completed to examine the most helpful strategies for caregivers when providing in-home palliative care (Aoun et al., 2005; Bottorff, Kelly & Young, 2005; Harding & Higginson, 2003; Kristjanson, 2005). This became an important reason for the researcher's attempt to access the caregivers' perspectives regarding what might be helpful interventions to promote sleep and rest while in the family caregiver role.

***Category I: Getting Through the Endless Day***

Family caregivers providing in-home palliative care were able to identify various strategies used during the day to help them, both physically and mentally, get through the long days of caregiving despite not receiving the usual quantity and quality of sleep at night. Days were described as extremely busy, starting early (i.e. between 0500 and 0700), and were compared to a treadmill – once you got up and on, you just kept going!

Caregivers in this study and others (Aranda & Hayman-White, 2001; Hudson, 2004; Mangan et al., 2003) talked about the element of time, how days were filled to overflowing, with little time for themselves. Caregivers frequently admitted they were too busy to think about being tired. While exhausting, the relentless demands of caregiving helped push them through the days (Cain et al., 2004). The basic care needs of the patients drove the days first and foremost (Aranda & Hayman-White, 2001; Scott et al., 2001), with the added pressures of employment, house and yard work, and care of other family members. Caregivers in the current study as well as in other studies, tried to reframe the stressfulness of having limited time by recognizing that they were spending maximum time with their loved one (Jo et al., 2007).

Caregivers in the current study would compensate for feelings of tiredness, decreased energy, and diminished quality of life, by eating, seeking strength through prayer, taking short walks outside or planning a nap. Deliberate naps were limited, however, based on the sleep logs and narrative accounts, it was evident that given the opportunity, caregivers would attempt to rest or nap. In lieu of naps, they created short breaks to either stimulate or relax their minds by reading a book, playing solitaire, or working on a craft or puzzle.

Another strategy to survive the days was to prioritize activities, minimize interruptions, and avoid tasks that required a great deal of concentration. Caregivers utilized various strategies including, writing lists, keeping a date book or calendar, journals, and medication set-up trays to compensate for the decreased cognitive function secondary to sleep disturbance.

Many of the caregivers in the current study possessed an amazingly positive attitude which shone through in the current study's interviews with the researcher. Personality traits have been shown to play a role in overcoming some of the consequences affiliated with sleep disturbance. Caregivers' optimism has been reported to play a role in buffering the consequences of poor sleep and sustaining caregivers (Carter & Acton, 2006; Hudson, 2004). Carter and Acton (2006) report a negative correlation between caregiver mastery and sleep disturbance as well as a weak negative correlation between optimism and sleep disturbance. Secondary analysis of baseline data involving primary family caregivers (N = 35) of advanced cancer patients (Hudson, Hayman-White, Aranda, & Kristjanson, 2006) considered the role of self-reported competence versus self-reported anxiety, in predicting the sustainability of caregiving roles. The study suggested that the variable of competence plays a role in overcoming the challenges of caregiving.

While caregivers in the current study recognized the need for self-care they had to create opportunities to care for themselves in limited time. The bathtub was often a place of refuge (Williams, 2004). Respite services during the day offered a break from caregiving to rest, connect socially with others, enjoy time outside or to do errands, shopping and banking. Acceptance of available home care and volunteer services to provide respite is critical to sustaining in-home palliative care (Gomes & Higginson, 2006).

If available, shared family caregiving, appears to be a good strategy to encourage. Whether families members are close, like-minded in decision-making and able to work together to share the responsibility of care, and provide mutual support and respite,

determine the degree that they are able to sustain one another through the tiring days and nights of in-home palliative care (Gomes & Higginson, 2006). Conversely it was recognized that caregivers who felt alone in their role, doubted their ability to keep the patient at home due to exhaustion. These findings reinforce the findings of the current study. A number of participants described the benefits of sharing the caregiving role with another family member. This afforded the possibility of providing respite for each other during the day, taking turns to cover the nights, and not feeling alone at night when the patient's death is imminent.

Past experience (e.g., child-rearing, shift work) adapting to limited or varied sleep schedules, was viewed by participants as positively influencing how they managed in the current caregiving situation. The first of four principles of the Self-Efficacy Theory (Bandura, 1977), specifies that past history of performance accomplishments plays an important role in boosting confidence regarding one's ability to succeed. Previous work based on self-efficacy with family caregivers of advanced cancer patients has demonstrated that confidence and positive experiences may serve to buffer the caregiver distress associated with the emotional and physical demands of caregiving (Keefe, Ahles, Porter, et al., 2003). A sense of caregiving mastery (i.e. "I can handle this.") is reported as vital for successful caregiving (Jo et al., 2007) but certainly must be balanced by realistic expectations and attention to self-care.

### ***Category II: Getting Through the Restless Night***

Family caregivers in the current study identified strategies to optimize sleep during the night while caregiving. Extensive deliberation was evident regarding whether and when to take sleep medication. For the two of thirteen participants prescribed

medication, it was deemed effective in shutting down their busy minds, allowing them to fall asleep more quickly at bedtime and after being awakened in the early part of the night. One of these two participants chose not to take her medication when she was staying at the patient's home to assist with overnight care. The majority of advanced cancer caregivers in this study and in previous research, were adamant that they would avoid the use of sleep medication because it could hinder their ability to monitor the patient's needs throughout the night (Carter & Acton, 2006; Carter & Chang, 2000), or their readiness to respond competently to care needs.

Caregivers in this study sought alternatives to medication that would calm the mind and body to hasten sleep onset. Time to unwind – whether it was having a bath, reading, watching television, listening to music, praying, using muscle stimulation/relaxation techniques, and establishing some type of bedtime routine, was identified as being important to caregivers. Similar approaches have been explored in two family caregiver intervention studies reviewed by the researcher (Carter, 2006; McCurry, Logsdon, Vitiello, et al., 1998). Each study demonstrated that when family members were educated regarding the importance of sleep and sleep hygiene, and involved in choosing the best therapeutic approaches for their personal situation, positive changes were evident in their sleep parameters.

As reported in Chapter Five, caregivers frequently used cell phones or baby monitors to aid their vigilance over the patient. These devices and/or the 'mixed blessing' that they represented in relation to promoting sleep, was not discussed in the literature reviewed by the researcher.

Respite service was identified by the majority of study participants as an intervention that they would consider when needed. Bramwell and colleagues (1995) found that 70% of family caregivers connected to a community palliative care program would accept over-night respite service. At the time of the study interview, only two caregivers received outside over-night respite. During the three-day actigraphy data collection period, one additional caregiver started to receive over night relief. Actigraphy demonstrated that these caregivers slept an average of 6.74 hours per night when relieved of their caregiving role. In these cases, it was emphasized by family members, that effective respite service must be of high quality - the staff must be closely screened, highly trained, and organized in consistent patterns. In other words, the family would not relinquish the patient's care or fall asleep, unless they and the patient trusted the stranger in their midst. Authors of other studies have highlighted these important components in offering night service (Bramwell et al., 1995; Cain et al., 2004; Kristjanson et al., 2004). Kristjanson and colleagues (2004) undertook action research to develop, implement and evaluate a community hospice respite program in Australia. Studies such as this one and that of Bramwell et al. (1995) demonstrate that respite service may allow patients to remain at home longer while preserving the health of the caregiver, thereby serving a dual purpose.

### *Summary*

This section of Chapter Six, has attempted to connect the findings which emerged from the caregivers' narratives to existing knowledge. The overarching theme of *Sleeping With One Eye Open*, the sub-themes, *Contributing Factors to Family Caregivers' Sleep Disturbance*, *Consequences of Family Caregivers' Sleep Disturbance*, and *Strategies to*

Overcome Sleep Disturbance, and the related categories and sub-categories have been discussed, drawing on existing published literature. New information has been highlighted, as well as the findings that prompt recommendations for future work.

### *Discussion of Prominent Quantitative Findings*

Quantitative findings in this study were generated from the two self-report instruments, the Epworth Sleepiness Scale (ESS) and the Pittsburgh Sleep Quality Index (PSQI), as well as the objective measurement of sleep/wake patterns through actigraphy. It is interesting to compare these findings across the instruments and approaches utilized here as well as the findings documented in the literature.

#### *Epworth Sleepiness Scale*

As noted in Chapter 5, based on ESS results, five of the thirteen participants demonstrated excessive daytime sleepiness with scores  $\geq 11$  (on possible range 0 - 21). Interestingly, the PSQI also revealed that five of the thirteen participants scored higher than the desired range for the daytime dysfunction component. However, only two of the five participants overlapped across both instruments. These findings suggest that potentially eight of the thirteen participants experienced daytime difficulty secondary to poor sleep. This greater number aligns with the observations of the researcher and the caregiver narratives shared during the research visits.

None of the family caregiver research studies reviewed utilized ESS to evaluate daytime sleepiness. For comparison then, the researcher searched for other relevant work. In a study conducted by Sharafkhaneh and Hirshkowitz (2003) to gather normative ESS values, the instrument was administered to four different groups: general non-patient population ( $n = 53$ ), geriatric population ( $n = 22$ ), medical residents providing on-call

service ( $n = 18$ ), and patients referred for sleep evaluation ( $n = 53$ ). The mean ESS scores for these for groups respectively were 7.6, 8.6, 12.0, and 15.2. The mean ESS score for the thirteen family caregivers in this study ( $M = 8.7$ ), indicated that their daytime sleepiness surpassed that of healthy adults, yet fell between that of older adults ( $M$  age = 78 years), and sleep-deprived medical residents ( $M$  age = 28 years) working nights. Another study (Manni et al., 1999) reported that adults diagnosed with obstructive sleep apnea ( $n = 54$ ) had a mean ESS of 11.7, and healthy adults matched for age and sex ( $n = 54$ ) had a mean ESS of 4.4. In comparison, the ESS ( $M = 8.7$ ) for the current study participants was significantly higher than that of the healthy adults in Manni's study, and below the mean ESS scores of individuals diagnosed with sleep apnea.

Despite the simplicity and brevity of the ESS, family members in the current study struggled to respond accurately to the eight scenarios for various reasons. The questions seemed irrelevant to many of them in their current caregiving situation (e.g., "I am too busy to sit and watch TV during the day." "I never have time to sit down after lunch.") The secondary literature review completed in conjunction with the discussion of the findings, illuminated the current debate regarding the strengths and weaknesses of EES.

While the ESS is highly-utilized and provides a standardized measurement across world-wide research and clinical practice, there are now questions as to its reliability and validity (Chervin, 2003; Tachibana & Taniguchi, 2007). Such questions arose in the current study. The researcher was perplexed to record total ESS scores of 6, 0, 6, and 2 for four participants, who appeared exhausted to the experienced eye of the researcher and described feeling extremely tired when responding to the interview questions.

Research in the general sleep community is examining the contextual factors that may affect the ESS scores and recommending improved utilization guidelines (Sharafkhaneh & Hirshkowitz, 2003). Nurse researchers studying sleep disturbance in the cancer patient and family caregiver populations have also recognized the need for further consideration and guidelines to ensure the 'fit' and reliability of ESS when matching this tool to specific research questions or clinical concerns (Berger et al., 2005).

### ***Pittsburgh Sleep Quality Index***

While ESS has had limited use in existing family caregiver research, the PSQI has been widely utilized. The PSQI findings of this current study echoed those of other studies involving family caregivers of cancer patients (Carter, 2002; Carter, 2003; Carter & Chang, 2000). In each of these past studies as well as the current study, caregivers reported moderate to severe sleep problems for six of the seven component scores. These studies also reported the lowest component score regarding use of sleep medications. As in previous studies, the thirteen caregivers in the current study reported a hesitancy to use sleep medications. They shared their fears that, if they took sleep medication, they might not hear the patient during the night or they might be incapable of providing the necessary care. Based on PSQI findings, the current study reported that 100% of the participants reported moderate to severe sleep disturbance while Carter and Chang (2000) reported 95% of the advanced cancer caregivers reported moderate to severe sleep problems. These findings are consistent with the caregiver narratives when taken as a whole. A small number of participants in the current study claimed they were able to obtain sufficient sleep, yet there was evidence of inconsistencies in their comments throughout the transcripts related to their actual sleep quality and quantity.

### *Actigraphy*

In a previous study combining PSQI and actigraphy data collection with caregivers of advanced cancer patients, Carter (2003) documented that actigraphy successfully captured information beyond that obtained by PSQI. Combining the two data sources (PSQI and actigraphy) in the current study also generated interesting observations and comparisons.

In contrast to Carter's work (2003), the thirteen caregivers in this study *underestimated* the amount of sleep they were obtaining. The PSQI estimated sleep duration or total sleep time ( $M = 5.31$  hours) was lower than the total sleep time per night measured by actigraphy ( $M = 6.67$  hours). The PSQI sleep efficiency estimates by caregivers ( $M = 70.25\%$ ) also proved to be lower than the sleep efficiency scores generated from the actigraphy data analysis ( $M = 84.78\%$ ). Therefore the caregivers in the current study were consistently underestimating the amount of sleep they were acquiring. The researcher wonders if this is based on their perception of tiredness resulting from their interrupted sleep experience and possible non-restorative sleep experience.

While the caregivers in the current study underestimated sleep quantity, Carter (2003) reported that caregivers overestimated sleep quantity. The caregivers in her study reported an average of 6.05 hours of sleep per night (sleep efficiency = 80%), while actigraphy measured mean sleep duration of 4.83 hours per night (sleep efficiency = 74%). Regardless, both studies demonstrate that family caregivers' sleep quantity per night (whether self-reported or objectively measured) is still under the desired 7 - 8 hours (Lee, 2003).

It is interesting to note that the actigraphy findings from the current study are more consistent with those of Kushida and colleagues (2001) who compared actigraphy, polysomnography and subjective self-report findings. Their study sample involved middle-aged and older patients, known to have some form of sleep disorder. Actigraphy produced over-scores of 1.0-1.8 hours per night of actual sleep and sleep efficiencies greater by 12% to 29%, when compared to polysomnography. It is important to note that Kushida et al. (2001) found that actigraphy overscored actual sleep time to a greater degree than subjective self-reports when both were compared to polysomnography. The challenge with actigraphy is that 'quiet time' may be misinterpreted as sleeping time (Ancoli-Israel, 2003; Lichstein et al., 2006).

Sleep latency reported in the current study's PSQI findings was slightly beyond the desired range of 0-1 ( $M = 1.23$ ) and consistent with the study's actigraphy sleep latency mean score of 18.67 minutes (slightly beyond the desired maximum time of 15 minutes). One might have expected this sleep latency score to be higher, based on the caregiver narratives describing their 'busy minds.' However, their narrative accounts also depicted their exhaustion by days end, and that "nothing could keep me awake!" These current study results are supported by the current understanding of the homeostatic process of normal sleep [as described in Chapter 2, p. 11]. The prior amount of sleep and wakefulness determines sleep propensity (Roehrs, 2000). The reduction of sleep time the previous night directly increases the speed of falling asleep, thus reducing sleep latencies the following.

Interviews with family caregivers in the current study, revealed the difficulty experienced by caregivers in returning to sleep if they were awakened during the night.

Thesis findings are consistent with those of Flakerud and colleagues (1999) who found that caregivers of cancer patient had less problems falling asleep but experienced a more restless sleep and had trouble staying asleep or returning to sleep if awakened, when compared to caregivers of patients with HIV/AIDS or dementia. This narrative data is supported by the actigraphy data in the current study. The mean WASO score ( $M = 41.93$  minutes) represents the time awake after sleep onset. This time is significant considering the shortened total sleep time already reported.

Actigraphy proved to be an excellent objective measure of sleep interruption throughout the night, when compared to subjective self-reports (Kushida et al., 2001). The mean movement/fragmentation score for family caregivers in this study was surprisingly high at 11.61 (time per night). This movement included getting up to assist with patient care, the caregiver's own bathroom routine, patient, and caregiver restlessness. Regardless of the reason, the scores illustrate the potential for diminished sleep quality as well as quantity. When sleep is fragmented, normal characteristics of sleep are altered and the ultradian process affected. These caregivers may not have experienced restorative sleep which progresses through the normal stages and cycles [as described in Chapter 2, p.11]. For example, normal adults enter sleep through NREM sleep which usually lasts at least 80 minutes before shifting to REM sleep (Kryger et al., 2005). This is followed by NREM-REM cycles of about 90 minutes in length throughout the night. The narratives, actigraphy, and sleep logs illustrate that night-time sleep for family caregivers is predominantly fragmented and broken into sleep episodes of less than 60 minutes (i.e., < 80 - 90 minute cycles). Caregivers comments such as...

*“I am usually awakened within an hour of falling asleep as my husband takes his morphine at midnight, and then we may be up an hour later if he needs to go to the bathroom..”*

...support the actigraphy movement/fragmentation findings.

Napping as part of the caregivers' sleep/wake patterns is an interesting phenomenon in this study, however the published caregiver literature reviewed by the researcher did not address napping. In the current study, caregivers reported a limited number of intentional naps. A scan of the sleep logs revealed that only four of the thirteen participants recorded one nap ( $\geq 20$  minutes) in the 72-hour period. One participant reported four naps ( $\geq 20$  minutes) in 72-hours. This caregiver shared in the interview that the 72-hour recording period for the study coincided with a weekend of respite which allowed him to catch up on his sleep, unlike his usual weekday routine.

Seemingly different to the caregivers' sleep log data, the actigraphy data revealed more naps per day ( $M = 4.81$ ). However, less than one of these naps per day ( $M = .81$ ) was greater than 20 minutes, which is consistent with the sleep log reports. Recall from Chapter 2, p. 12, that to be restorative, a nap should be at least 20 - 30 minutes in length (Kryger et al., 2005). Therefore, many of these micro naps captured by actigraphy data are not restorative in nature, but perhaps a reflection of the degree of daytime sleepiness of these family caregivers. Given that previous work has reported that micro naps and periods of inactivity captured by actigraphy, are indicative of daytime sleepiness (Littner et al., 2003), the actigraphy data of the current study would suggest that daytime sleepiness was prevalent in this caregiver population. This was also consistent with the narratives and PSQI findings from the thirteen family caregivers. It was evident that many of these naps occur in the evening hours when caregivers reported that they were

exhausted from the day's activities. Considered as a whole, the narratives, sleep logs and actigraphy findings from the current study suggest that, given the opportunity, caregivers would nap to catch up on their sleep. It has also become evident that napping during family caregiving deserves further attention.

### *Correlations*

Two significant correlations emerged from the statistical analysis that explored relationships between the current study's variables and data sources. These correlations suggested that as the patients' Palliative Performance Score (PPS) declined (0% associated with death), family caregivers' sleep latency (actigraphy) increased ( $r = -0.903; < .01$ ) and family caregivers' movement/fragmentation index increased ( $r = -0.842; < .01$ ). As the patients' condition declines the family caregivers experienced more difficulty getting to sleep and staying asleep or obtaining uninterrupted sleep. These findings are consistent with previous research findings in this area (Bramwell, et. al., 1995; Kristjanson et al., 2004). Similar to this current study findings, Kristjanson and colleagues reported that the most prevalent patient diagnosis was lung cancer and the most prevalent patient conditions which prompted over-night respite was patients' restlessness and patients' incontinence/toileting problems. The findings of this Australian study, suggest that as the patients' condition deteriorates, caregiver exhaustion and stress increases.

Therefore this study clearly indicates the value of over-night respite to sustain in-home palliative care provision. In addition to the quantitative data cues, another 'cue' emerged from the caregiver narratives in the current study indicative of the need for over-night respite, that of a 'couch-night'. Once the caregivers assessed the patients' situation

as requiring the frequency of attention and assistance embodied in a 'couch-night', overnight respite from other family members or home care services is likely required to sustain the intensity of in-home palliative care provision.

### **Reflection on Theoretical Perspectives**

As outlined in Chapter Three, symbolic interactionism (Blumer, 1969; Mead, 1964) and the Symptom Management Model (SMM) (Dodd et al., 2001) formed the theoretical underpinning of this family caregiver study. Throughout the interviews and analysis of the family caregiver narratives, the complexity of the caregivers' sleep experience became evident. The contextual interactions between caregivers and patients, between family members, between patients and health care providers, and family and health care providers, all contributed to the actual sleep experience of the caregivers. In addition, the common denominator for all caregivers of caring for a dying relative at home created a shared sense of knowing, meaning and language between the participants. For example, phrases like 'going crazy', 'couch night', 'sleeping with one eye open', 'too busy to be tired', 'making do with what I get', 'self-sacrifice', and 'the monitor,' surfaced across the interviews as a form of a common language, holding the same meaning for participants. The perspective of symbolic interactionism prompted the recognition of the shared sleep disturbance experience of these family caregivers – it comprised their related attitudes, behaviours, words, and actions.

In returning to the dimensions and concepts of the SMM after the analysis and discussion of the study findings, it was quite remarkable to note the similarities between the model and the findings. The sub-themes, categories, sub-categories and relationships of the findings echoed those within the SMM. A couple of exemplars illustrate this

resemblance. In SMM the person dimension is divided into demographic, psychological, physiological, and sociological components. These components were congruent with the categories which emerged under the caregiver sleep disturbance antecedent factors, as well as the categories that emerged in the consequences of sleep disturbance. Secondly, the symptom outcomes including quality of life, functional status, emotional status, self-care, and job performance were the salient consequences identified by the family caregivers.

Consider also the concept of adherence, depicted in Figure 3.1 [p. 35] to affect the relationship between Symptom Management and Symptom Outcomes in the SMM model. The concept of adherence is a critical factor in the outcome of the interventions. Adherence refers to whether the intended recipient of the intervention actually receives or uses the strategy prescribed. It can be controlled by the patient or family member who is the target of the intervention or, it can be influenced by the health care provider and health care system. Considering the findings of this study, the reluctance of the patient and/or the family caregiver to accept in-home palliative care services such as respite, controls to a certain degree whether the intervention is utilized or successful in ameliorating family caregiver sleep disturbance. This adherence (a.k.a. reluctance) is also affected by the health care system as it depends largely on the timing, availability and quality of the respite services.

In summary, both theoretical perspectives proved to be very helpful in the design, analysis and discussion of the findings in this study. The researcher is further convinced that SMM would be useful in future sleep assessment and intervention studies.

### **Limitations of the Study**

The three main limitations of this study are related to the sample, the novice level of the researcher, and the cross-sectional nature of the study.

The small sample size limited the extent of data analysis of the quantitative data, as well as its generalizability. Other sample limitations relate to the predominantly white Anglo-Saxon, female sample, whose dying relatives were already registered with community palliative care services. Thus, this study does not reflect the nature of sleep disturbance within perhaps more vulnerable populations who have not accessed services through the regional health authorities. Therefore, the perspectives of the study participants may not represent the broader population of caregivers.

Being a novice researcher, hindsight reveals that minor adjustments in the study's design and implementation could have further strengthened the data set. For example, the use of a five-point Likert scale as well as a word descriptor of the participants' health status self-report, would have been beneficial. As a novice research interviewer, richer narratives could possibly have been obtained with more experience in eliciting the caregivers' feelings and thoughts and by improving cues and probes.

The cross-sectional nature of this study is also viewed as a limitation, as data was captured at a single point in time during the caregiving period. Many temporal factors require acknowledgement, given the timing and environment of data collection with family caregivers providing care to a dying relative. Participants were asked to reflect "on the previous month" for the PSQI and "life in recent times" on the ESS. The study will only present a 'snapshot' of the caregivers' sleep disturbance within a short period of three days of caregiving. The researcher is aware that potentially very different findings

may have been obtained depending on the timing of the three-day actigraphy component for a couple of participants. For example, one interview occurred on a Friday which meant that the actigraphy data was collected over the following three days which happened to coincide with weekend respite intended for the caregiver to catch up on sleep. For another participant, night-time respite started during the three-day actigraphy data collection, which may have also altered the findings. However, the study still provided practical experience and information regarding the feasibility of using actigraphy as a data collection method in this caregiver population. It is certainly acknowledged that richer data sets are produced through longitudinal research. In one such study, Carter (2003) found that caregiver symptoms such as sleep disturbance and depression fluctuated greatly from week to week as they were affected by many internal and external factors.

Other temporal concerns related to data collection were acknowledged by the research participants. If caregivers were still able to sleep fairly well, they related that it was difficult for them to anticipate what services, information, or support might be most helpful or what they would utilize in the future. Also, when caregivers were asked to recommend intervention strategies for the health care system to develop, they had difficulty articulating what the system could do for them while they were tired and in the midst of caregiving. As noted by Sandelowski (1999) introspection is challenging for participants. Study participants often require sufficient time after the target event to process and articulate the experience.

Another temporal aspect inherent in a palliative study of this nature is that the intensity of the situation may negatively impact their willingness to participate in both the

interview and actigraphy/sleep log components of the study. However, only one of the caregivers referred to the study declined to participate, due to the intensity of the situation, and only one participant declined to participate in the actigraphy portion for a similar reason. It is important to note however that the researcher is unaware of the number of caregivers who declined participation following the palliative care coordinator's initial recruitment. Similar to the experience of Carter (2003), this study demonstrated that the participants were very keen to participate in the actigraphy and committed to completing the sleep log in a comprehensive manner. The family caregivers voiced genuine appreciation and were intrigued by this focused attention on themselves, and were anxious to learn the results, particularly from the actigraphy analysis.

### **Recommendations**

#### ***Nursing Practice:***

1. Assessment of the patient and caregiver's sleep status must be impeccable.
2. The importance of sleep and sleep hygiene should be highlighted when educating caregivers.
3. Nurses should develop culturally-sensitive educational handouts regarding sleep, sleep hygiene and intervention strategies at an appropriate comprehension level.
4. To optimize their sleep and rest, patient and family care plans should include sleep intervention strategies suited to their personal goals and situations. These should include non-pharmacological and pharmacological approaches.
5. Nurses should develop and coordinate round-the-clock services, including professional visits, respite, and auxiliary home help for laundry, cleaning, and linen changes to off load the energy expenditure of the caregiver.

6. Careful assessment and advance planning is mandatory to provide timely and appropriate respite service.
7. Patients and families must be continually provided with information regarding the type, availability, cost, and eligibility criteria for home services, as well as the communication loop for feedback regarding suitability of service.
8. Colleagues on the palliative care team should equally benefit with timely education regarding sleep, sleep hygiene, sleep assessment and intervention strategies.
9. Excellent screening, selection, and education of direct service workers regarding palliative care is of utmost importance to ensure quality home care.
10. Nurses must assess and attend to a complete range of factors and be ready to perform a myriad of interventions to alleviate sleep disturbance, including:  
impeccable assessment and optimal symptom management for the palliative patient;  
consider the caregivers' psychosocial status and care needs; advance care planning discussions and paper work; education regarding care for a dying family member at home and signs of approaching death; and if necessary, advocate for family members time from work.
11. Above all, nurses must be ready to advocate on behalf of family caregivers.

***Nursing Education:***

1. Nursing curricula should include content related to sleep, sleep physiology, and sleep pathophysiology, emphasizing the importance of sleep to health and well-being. Course and clinical content should include the assessment of sleep status and those at risk for sleep disturbance, the importance of patient/family education

related to sleep hygiene, and a wide range of pharmacologic and non-pharmacologic sleep interventions.

2. Continuing education and staff development programs for nursing should include content related to the sleep topics listed in #1.
3. It is critical that current research evidence, including the findings of this study, be integrated into nursing and interdisciplinary education, as well as practice. The dissemination of these findings through peer-reviewed publications, conferences and educational rounds to others involved in palliative care provision and beyond, is an important component of research work of this nature.

***Nursing Research:***

1. Studies in advanced cancer patient and caregiver populations should be considered a research priority. Sleep assessment and management is an important component of holistic care, and appears to play a vital role in the health and well-being of both patient and caregiver and the feasibility of providing in-home palliative care.
2. Studies are required which develop and adapt, as well as test and refine, sleep assessment tools and sleep interventions that will be relevant to palliative care patients and families. Interventions include pharmacologic and non-pharmacologic approaches, as well as support services designed to provide respite specifically for sleep and rest for family caregivers. Further research is also required related to restorative naps for caregivers.
3. Studies should include outcome variables, such as perceived quality of life, functional status, and related symptoms to further understand the significance of sleep and sleep disturbance in the palliative care patient and caregiver populations.

## Conclusion

Findings from this study provide a greater understanding of the experience of sleep disturbance while providing care to a dying relative in the home setting. While it was challenging for a novice researcher to mesh the two methodological approaches, the quantitative data served to enrich the personal stories shared in the caregiver interviews. The majority of the findings validate those of previous work. However, new and contrasting data has also been highlighted. The theoretical perspectives of symbolic interactionism and the Symptom Management Model proved to be very helpful in guiding this work. Limitations have been noted in this chapter's final discourse, and recommendations for future nursing practice, education and research have been proposed.

Despite the numerous positive aspects of extending family relationships to include palliative caregiving, it is critical that we attend to the potential negative consequences for family caregivers as we continue the shift from institutional to community care. The interest and willingness of family caregivers to participate in this research study in the midst of providing home-based palliative care dispels past hesitancy to further 'burden' them, and encourages us to involve families of the dying in our quest for improved palliative care interventions (Hudson, 2003).

## References

- Allen, R. E. (Ed.). (1990). *The concise Oxford dictionary* (8<sup>th</sup> ed.). London: Clarendon Press.
- Ancoli-Israel, S. (2005). Sleeping and aging: prevalence of disturbed sleep and treatment considerations in older adults. *Journal of Clinical Psychiatry, 66*, 24-30.
- Ancoli-Israel, S., Cole, R., Alessi, D., Chambers, M., Moorcroft, W., & Pollak, C. P. (2003). The role of actigraphy in the study of sleep and circadian rhythms. *Sleep, 26*, 342-355.
- Anderson, F., Downing, G. M., Hill, J., Casorso, L., & Lerch, N. (1996). Palliative performance scale (PPS): a new tool. *Journal of Palliative Care, 12*, 5-11.
- Aoun, S. M., & Kristjanson, L. J. (2005). Caregiving for the terminally ill: at what cost? *Palliative Medicine, 19*, 551-555.
- Aranda, S. K., & Hayman-White, K. (2001). Home caregivers of the person with advanced cancer. *Cancer Nursing, 24*, 300-307.
- Aranda, S. K., & Milne, D. (2000). *Guidelines for the assessment of complicated bereavement risk in family members of people receiving palliative care*. Melbourne: Centre for Palliative Care.
- Arno, P. S., Levine, C., & Memmott, M. M. (1999). The economic value of informal caregiving. *Health Affairs (Millwood), 18*(2), 182-188.
- Ayres, L., Kavanaugh, K., & Knafl, K. A. (2003). Within-in case and across-case approaches to qualitative data analysis. *Qualitative Health Research, 13*, 871-883.
- Bandura, A. (1977). Self-efficacy: toward a unifying theory of behavioral change. *Psychological Review, 84*, 191-215.
- Beck, S. L., Dudley, W. N., & Barsevick, A. (2005). Pain, sleep disturbance, and fatigue in patients with cancer: using a mediation model to test a symptom cluster. *Oncology Nursing Forum, 32*, E48-E55.
- Berger, A. M., Parker, K. P., Young-McCaughan, S., Mallory, G. A., Barsevick, A. M., Beck, S. L., et al. (2005). Sleep/wake disturbances in people with cancer and their caregivers: state of the science. *Oncology Nursing Forum, 32*, E98-E126.
- Berger, A. M., Sankaranarayanan, J., & Watanabe-Galloway, S. (2006). Current methodological approaches to the study of sleep disturbances and quality of life in adults with cancer: A systematic review. *Psycho-Oncology* [On-line]. Available: [www.interscience.wiley.com](http://www.interscience.wiley.com)

- Boeije, H. (2002). A purposeful approach to the constant comparative method in the analysis of qualitative interviews. *Quality & Quantity*, 36, 391-409.
- Bottorff, J. L., Kelly, M., & Young, J. (2005). Methodological issues in researching palliative care nursing practice. *Canadian Journal Nursing Research*, 37, 50-68.
- Bramwell, L., Mackenzie, J., Laschinger, H., & Cameron, N. (1995). Need for overnight respite for primary caregivers of hospice clients. *Cancer Nursing*, 18, 337-343.
- Brummet, B. H., Babyak, M. A., & Siegler, I. C. (2006). Associations among perceptions of social support, negative affect, and quality of sleep in caregivers and noncaregivers. *Health Psychology*, 25, 220-225.
- Buysse, D. J., Reynolds, C. F., Monk, T. H., Berman, S. R., & Kupfer, D. J. (1989). The Pittsburgh Sleep Quality Index (PSQI): A new instrument for psychiatric research and practice. *Psychiatry Research*, 28, 193-213.
- Cain, R., MacLean, M., & Sellick, S. (2004). Giving support and getting help: informal caregiver's experiences with palliative care services. *Palliative and Supportive Care*, 2, 265-272.
- Carpenter, J. S., & Andrykowski, M. A. (1998). Psychometric evaluation of the Pittsburgh Sleep Quality Index. *Journal of Psychometric Research*, 45, 5-13.
- Carter, P. A. (2002). Caregivers' descriptions of sleep changes and depressive symptoms. *Oncology Nursing Forum*, 29, 1277-1283.
- Carter, P. A. (2003). Family caregivers' sleep loss and depression over time. *Cancer Nursing*, 26, 253-259.
- Carter, P. A. (2005). Bereaved caregivers' descriptions of sleep: impact on daily life and the bereavement process. *Oncology Nursing Forum*, 32, E70-E75.
- Carter, P. A. (2006). A brief behavioral sleep intervention for family caregivers of persons with cancer. *Cancer Nursing*, 29, 95-103.
- Carter, P. A., & Acton, G. J. (2006, February). Personality and coping: predictors of depression and sleep problems among caregivers of individuals who have cancer. *Journal of Gerontological Nursing*, 45-53.
- Carter, P. A., & Chang, B. L. (2000). Sleep and depression in cancer caregivers. *Cancer Nursing*, 23, 410-415.
- Casarett, D. J., & Karlawish, J. H. T. (2000). Are special ethical guidelines needed for palliative care research? *Journal of Pain and Symptom Management*, 20, 130-139.
- Chang, E. W., Tsai, Y. Y., & Tsao, C. J. (2007). Quality of sleep and quality of life in caregivers of breast cancer patients. *Psycho-Oncology* (in press).

- Cohen, R., Leis, A. M., Kuhl, D., Charbonneau, C., Ritvo, P., & Ashbury, F. D. (2006). QOLLI-F: measuring family carer quality of life. *Palliative Medicine*, 20, 755-767.
- Chuman, M. (1983). The neurological basis of sleep. *Heart and Lung*, 12, 177-181.
- Cook, T. D., & Campbell, D. T. (1979). *Quasi-experimentation: Design & analysis for field setting*. Boston: Houghton Mifflin Company.
- Davidson, J. R., MacLean, A. W., Brundage, M. D., & Schulze, K. (2002). Sleep disturbance in cancer patients. *Social Science & Medicine*, 54, 309-321.
- Dean, R. A., & McClement, S. E. (2002). Palliative care research: methodological and ethical challenges. *International Journal of Palliative Nursing*, 8, 376-380.
- Deeken, J. F., Taylor, K. L., Mangan, P., Yabroff, K. R., & Ingham, J. M. (2003). Care for the caregivers: a review of self-report instruments developed to measure the burden, needs, and quality of life of informal caregivers. *Journal of Pain and Symptom Management*, 26, 922-953.
- Degner, L. F., & Sloan, J. A. (1995). Symptom distress in newly diagnosed ambulatory cancer patients and as a predictor of survival in lung cancer. *Journal of Pain and Symptom Management*, 10, 423-431.
- DiCicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. *Medical Education*, 40, 314-321.
- Dodd, M., Janson, S., Facione, N., Faucett, J., Froelicher, E. S., Humphrey, J., et al. (2001). Advancing the science of symptom management. *Journal of Advanced Nursing*, 33, 668-676.
- Dodd, M., Miaskowski, C., & Paul, S. (2001). Symptom clusters and their effect on the functional status of patients with cancer. *Oncology Nursing Forum*, 28, 465-470.
- Duke, S. (1998). An exploration of anticipatory grief: the lived experience of people during their spouses' terminal illness and in bereavement. *Journal of Advanced Nursing*, 28, 829-839.
- Dunbrack, J. (2003). *Information needs of family caregivers involved in palliative and end-of-life care in Canada*. Ottawa: Health Canada.
- Edwards, M., & Chalmers, K. (2002). Double agency in clinical research. *Canadian Journal of Nursing Research*, 34, 131-142.
- Efrainsson, E., Hoglund, I., & Sandman, P. (2001). 'The everlasting trial of strength and patience': transitions in home care nursing as narrated by patients and family members. *Journal of Clinical Nursing*, 10, 813-819.

- Emanuel, E. J., Fairclough, D. L., Slutsman, J., & Emanuel, L. L. (2000). Understanding economic and other burdens of terminal illness: the experience of patients and their caregivers. *Annals of Internal Medicine*, 132, 451-459.
- Engstrom, C. A., Strohl, R. A., Rose, L., Lewandowski, L., & Stefanek, M. E. (1999). Sleep alterations in cancer patients. *Cancer Nursing*, 23, 143-148.
- Fast, J. E., & Keating, N. C. (2000). *Family caregiving and consequences for carers: toward a policy research agenda*. Ottawa: Canadian Policy Research Networks, Inc.
- Flaskerud, J. H., Carter, P. A., & Lee, P. (2000). Distressing emotions in female caregivers of people with AIDS, age-related dementias, and advanced-stage cancers. *Perspectives in Psychiatric Care*, 36, 121-130.
- Flaskerud, J. H., & Tabora, B. (1998). Health problems of low income female caregivers of adults with HIV/AIDS. *Health Care for Women International*, 19, 23-26.
- Gomes, B., & Higginson, I. J. (2006). Factors influencing death at home in terminally ill patients with cancer: systematic review. *British Medical Journal*, 332, 515-521.
- Guba, E. G., & Lincoln, Y.S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp.105-117). Thousand Oaks: Sage.
- Haley, W. E. (2003). The costs of family caregiving: implications for geriatric oncology. *Critical Reviews in Oncology/Hematology*, 48, 151-158.
- Happe, S., & Berger, K. (2002). The association between caregiver burden and sleep disturbances in partners of patients with Parkinson's disease. *Age and Ageing*, 31, 349-354.
- Harding, R., & Higginson, I. J. (2003). What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliative Medicine*, 17, 63-74.
- Hawryluck, L. (2004). People at the end of life are a vulnerable research population. *Clinical Oncology*, 16, 225-226.
- Hayman, J. A., Langa, K. M., Kabeto, M. U., Katz, S. J., DeMonner, S. M., Chernew, M. E., et al. (2001). Estimating the cost of informal caregiving for elderly patients with cancer. *Journal of Clinical Oncology*, 19, 3219-3225.
- Hearson, B. (in press). Sleep disturbance in family caregivers. *International Journal of Palliative Nursing*.

- Hearson, B. (in press). Sleep disturbance in advanced cancer patients: utilizing the Human Response to Illness Model to guide care. *International Journal of Palliative Nursing*.
- Heitkemper, M., & Shaver, J. (1989). Nursing research opportunities in enteral nutrition. *Nursing Clinics of North America*, 24, 415-426.
- Hudson, P. (1998). The educational needs of lay carers. *European Journal of Palliative Care*, 5, 183-186.
- Hudson, P. (2003). The experience of research participation for family caregivers of palliative care cancer patients. *International Journal of Palliative Nursing*, 9, 120-123.
- Hudson, P. (2004). Positive aspects and challenges associated with caring for a dying relative at home. *International Journal of Palliative Nursing*, 10, 58-65.
- Hudson, P., Aranda, S., & Kristjanson, L. (2004a). Information provision for palliative care families. *European Journal of Palliative Care*, 11, 153-157.
- Hudson, P. L., Aranda, S., & Kristjanson, L. J. (2004b). Meeting the supportive needs of family caregivers in palliative care: challenges for health professionals. *Journal of Palliative Medicine*, 7, 19-25.
- Hudson, P. L., Hayman-White, K., Aranda, S., & Kristjanson, L. J. (2006). Predicting family caregiver psychosocial functioning in palliative care. *Journal of Palliative Care*, 22, 133-140.
- Hugel H., Ellershaw J. E., Cook, L., Skinner, J., & Irvine, C. (2004). The prevalence, key causes and management of insomnia in palliative care patients. *Journal of Pain and Symptom Management*, 27, 316-321.
- Jean-Louis, G., Kripke, D. F., Cole, R. J. A. J. D., & Langer, R. D. (2001). Sleep detection with an accelerometer actigraph: comparisons with polysomnography. *Physiological Behaviour*, 72, 21-28.
- Jepson, C., McCorkle, R., Adler, D., Nuamah, I., & Lusk, E. (1999). Effects of home care on caregivers' psychological status. *Image: Journal of Nursing Scholarship*, 31, 115-120.
- Jo, S., Brazil, K., Lohfeld, L., & Willison, K. (2007). Caregiving at the end of life: perspectives from spousal caregivers and care recipients. *Palliative and Supportive Care*, 5, 11-17.
- Johns, M. (1991). A new method for measuring daytime sleepiness: the Epworth Sleepiness Scale. *Sleep*, 14, 540-545.

- Johns, M. W. (1992). Reliability and factor analysis of the Epworth Sleepiness Scale. *Sleep, 15*, 376-381.
- Johns, M. W., & Hocking B. (1997). Daytime sleepiness and sleep habits of Australian workers. *Sleep, 20*, 844-949.
- Judd, D. (1994). *Give sorrow to words- working with a dying child* (2<sup>nd</sup> ed.). London: Whurr Publishers.
- Keefe, F. J., Ahles, T. A., Porter, L. S., Sutton, L. M., McBride, C. M., Pope, M. S., et al. (2003). The self-efficacy of family caregivers for helping cancer patients manage pain at end-of-life. *Pain, 103*, 157-162.
- Kiejna, A., Rymaszewska, J., Wojtyniak, B., & Stokwieszewski, J. (2004). Characteristics of sleep disturbances in Poland - results of the National Health Interview Survey. *Acta Neuropsychiatrica, 16*, 124-129.
- Kissane, D. W. (2004). Bereavement. In D. Doyle, G. Hanks, N. Cherney, & K. Calman (Eds.), *Oxford textbook of palliative medicine* (3<sup>rd</sup> ed., pp. 731-746). Oxford University Press: New York.
- Knop, D. S., Bergman-Evans, B., & McCae, B. W. (1998). In sickness and in health: an exploration of the perceived quality of the marital relationship, coping, and depression in caregivers of spouses with Alzheimer's Disease. *Journal of Psychosocial Nursing and mental health Services, 36*, 16-21.
- Koch, T. (2006). Establishing rigour in qualitative research: the decision trail. *Journal of Advanced Nursing, 19*, 976-986.
- Koopman, C., Nouriani, B., Erickson, V., Anupindi, R., Butler, L. D., Bachmann, M. H., et al. (2002). Sleep disturbances in women with metastatic breast cancer. *The Breast Journal, 8*, 362-370.
- Kristjanson, L. J. (2005). Directions in palliative care nursing research: impeccable care, timing, and complexity. *Canadian Journal of Nursing Research, 37*, 13-20.
- Kristjanson, L. J., Cousins, K., White, K., Andrews, L., Lewin, G., Tinnelly, C., et al. (2004). Evaluation of a night respite community palliative care service. *International Journal of Palliative Care Nursing, 10*, 84-90.
- Kryger, M. H., Roth, T., & Dement, W. C. (2005). *Principles and practice of sleep medicine* (4<sup>th</sup> ed.). Elsevier Saunders, Philadelphia.
- Kuwano, S., Mizunami, T., Namba, S., & Morinaga, M. (2002). The effect of different kinds of noise on the quality of sleep under controlled conditions. *Journal of Sound and Vibration, 277*, 83-90.

- Kushida, C. A., Chang, A., Gadkary, C., Guilleminault, C., Carrilo, O., & Dement, W.C. (2001). Comparison of actigraphic, polysomnographic, and the subjective assessment of sleep parameters in sleep disordered patients. *Sleep Medicine, 2*, 389-396.
- Kvale, E. A., & Shuster, J. L. (2006). Sleep disturbance in supportive care of cancer: a review. *Journal of Palliative Medicine, 9*, 437-450.
- Lac, G., & Chamoux, A. (2004). Biological and psychological responses to two rapid shiftwork schedules. *Ergonomics, 47*, 1339-1349.
- Larson, P. J., Carrieri-Kohlman, V., Dodd, M. J., Douglas, M., Faucett, J., Froelicher, E. S., et al. (1994). A Model for Symptom Management. *Image: Journal of Nursing Scholarship, 26*, 272-276.
- Lazarus, R., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.
- Lee, J. (1997). Balancing elder care responsibilities and work: two empirical studies. *Journal of Occupational Health Psychology, 2*, 220-228.
- Lee, K. A. (2003). Impaired sleep. In V. Carrieri-Kohlman, A. Lindsay, & C. West (Eds.), *Pathophysiological Phenomena in Nursing: Human Response to Illness* (pp.363-385). St. Louis: Saunders - Elsevier Science.
- Lee, K., Cho, M., Miaskowski, C., & Dodd, M. (2004). Impaired sleep and rhythms in persons with cancer. *Sleep Medicine Reviews, 8*, 199-212.
- Lev, E. L., & McCorkle, R. (1998). Loss, grief, and bereavement in family members of cancer patients. *Seminars in Oncology Nursing, 14*, 145-151.
- Levin, R. D., Daehler, M. A., Grutsch, J. F., Quilton, J., Lis, D. G., Peterson, C., et al. (2005). Circadian function in patients with advanced non-small-cell lung cancer. *British Medical Journal, 93*, 1202-1208.
- Lichstein, K. L., Stone, K. C., Donaldson, J., Nau, S. D., Soeffing, J. P., Murray, D., et al. (2006). Actigraphy validation with insomnia. *Sleep, 29*, 232-239.
- Littner, M., Kushida, C., McDowell Anderson, W., Bailey, D., Berry, R., Davilla, D., et al. (2003). Practice parameters for the role of actigraphy in the study of sleep and circadian rhythms: an update for 2002. *Sleep, 26*, 337-341.
- Loiselle, C. G., Profetto-McGrath, J., Polit, D. F., & Beck, C.T. (2004). *Canadian essentials of nursing research*. Philadelphia: Lippincott Williams & Wilkins.
- Mangan, P. A., Taylor, K. L., Yabroff, K. R., Fleming, D. A., & Ingham, J. M. (2003). Caregiving near the end of life: unmet needs and potential solutions. *Palliative and Support Care, 1*, 247-259.

- Manni, R., Politini, L., Ratti, M., & Tartara, A. (1999). Sleepiness in obstructive sleep apnea syndrome and simple snoring evaluated by Epworth Sleepiness Scale. *Journal of Sleep Research, 8*, 319-320.
- Marvasti, A.B. (2004). *Qualitative research in sociology: An introduction*. Thousand Oaks, California: Sage Publications.
- Maxwell, J. A. (2005). *Qualitative research design: An interactive approach*. Thousand Oaks, California: Sage Publications.
- McCance K. L., & Huether S. E. (2006). *Pathophysiology: The Biologic Basis for Disease in Adults and Children* (5<sup>th</sup> ed.). Elsevier Mosby: St. Louis.
- McCurry, S. M., & Teri, L. (1995). Sleep disturbance in elderly caregivers of dementia patients. *Clinical Gerontologist, 16*, 51-70.
- McCurry, S. M., Gibbons, L. E., Logsdon, R. G., & Teri, L. (2004, January). Awakenings in patients with Alzheimer's Disease. *Journal of Gerontological Nursing, 12* - 20.
- McEwen, M., & Wills, E. M. (2002). *Theoretical basis for nursing*. Philadelphia: Lippincott, Williams, & Wilkins.
- McKibbin, C. L., Ancoli-Israel, S., Dimsdale, J., Archuleta, C., von Kanel, R., Mills, P., et al. (2005). Sleep in spousal caregivers of people with Alzheimer's disease. *Sleep, 28*, 1245-1250.
- Meeker, M. A., & Jezewski, M. A. (2005). Family decision making at end of life. *Palliative and Supportive Care, 3*, 131-142.
- Mercadante, S., Girelli, D., & Casuccio, A. (2004). Sleep disorders in advanced cancer patients: prevalence and factors associated. *Supportive Care in Cancer, 12*, 355-359.
- Meyrick, J. (2006). What is good qualitative research? a first step towards a comprehensive approach to judging rigour/quality. *Journal of Health Psychology, 11*, 799-808.
- Mini Mitter Company, Inc. (2003). *Instruction manual: Software version 3.4 and earlier*. Bend, Oregon: Author.
- Mitchell, P. H., Gallucci, B., & Fought, S. G. (1991) Perspectives on human response to health and illness. *Nursing Outlook, 39*, 154-157.
- Moran, M., Lynch, C. A., Walsh, C., Coen, R., Coakley, D., & Lawlor, B. A. (2005). Sleep disturbance in mild to moderate Alzheimer's disease. *Sleep Medicine, 6*, 347-352.

- Mormont, M. C., Waterhouse, J., Bleuzen, P., Giacchetti, S., Jami, A., Bogdan, A., et al. (2000). Marked 24-h rest/activity circadian rhythms are associated with better quality of life, better response, and longer survival in patients with metastatic colorectal cancer and good performance status. *Clinical Cancer Research*, 6, 3038-3045.
- Oberst, M. T., Thomas, S. E., Gass, K. A., & Ward, S. E. (1989). Caregiving demands and appraisal of stress among family caregivers. *Cancer Nursing*, 12, 209-15.
- Osse, B. H., Vernooij-Dassen, M. J., Schade, E., Grol, R. P. (2005). The problems experienced by patients with cancer and their needs for palliative care. *Supportive Care Cancer*, 13, 722-732.
- NANDA International (2005). *Nursing diagnoses: Definitions and classification 2005-2006* (6<sup>th</sup> ed.). Philadelphia: Author.
- Pal, P. K., Thennarasu, K., Fleming, J., Schulzer, M., Brown, T., & Calne, S. M. (2004). Nocturnal sleep disturbances and daytime dysfunction in patients with Parkinson's disease and in their caregivers. *Parkinsonism and Related Disorders*, 10, 157-168.
- Pasacreta, J. V., & McCorkle, R. (2000). Cancer care: impact of interventions on caregiver outcomes. *Annual Review Nursing Research*, 18, 127-148.
- Payne, J. K., Piper, B. F., Rabinowitz, I., & Zimmerman, M. B. (2006). Biomarkers, fatigue, sleep, and depressive symptoms in women with breast cancer: a pilot study. *Oncology Nursing Forum*, 33, 775-783.
- Pearlman, L., Mullan, J., Semple, S., & Skaff, M. (1990). Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist*, 30, 583-594.
- Polit, D., & Beck, C. (2004). *Nursing research: principles and methods*, 7<sup>th</sup> ed. Philadelphia: Lippincott, Williams & Wilkins.
- Pruitt, R. H., & Privette, A. B. (2001). Methodological issues in nursing research: planning strategies for the avoidance of pitfalls in intervention research. *Journal of Advanced Nursing*, 35, 514-520.
- Rada, R. (2005). Obstructive sleep apnea and head and neck neoplasms. *Otolaryngological Head and Neck Surgery*, 132, 794-799.
- Riedel, B. W., & Lichstein, K. L. (2000). Insomnia and daytime functioning. *Sleep Medicine Reviews*, 4, 277-298.
- Roehrs, T. (2000). Sleep physiology and pathophysiology. *Clinical Cornerstone*, 2, 1-12.
- Rose, K. E. (1999). A qualitative analysis of the information needs of informal carers of terminally ill cancer patients. *Journal of Clinical Nursing*, 8, 81-88.

- Sanna, P., & Bruera, E. (2002). Insomnia and sleep disturbance. *European Journal of Palliative Care*, 9, 8-12.
- Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science*, 8, 27.
- Sandelowski, M. (1995). Sample size in qualitative research. *Research in Nursing & Health*, 18, 179-183.
- Sandelowski, M. (1999). Time and qualitative research. *Research in Nursing & Health*, 22, 79-87.
- Sateia, M. J., & Santulli, R. B. (2004). Sleep in palliative care. In D. Doyle, G. Hanks, N. Cherney, & K. Calman (Eds.), *Oxford textbook of palliative medicine* (3<sup>rd</sup> ed., pp. 731-746). Oxford University Press: New York.
- Savard, J., & Morin, C. M. (2001). Insomnia in the context of cancer: a review of a neglected problem. *Journal of Clinical Oncology*, 19, 895-908.
- Schumacher, K. L., Stewart, B. J., & Archbold, P. G. (1998). Conceptualization and measurement of doing family caregiving well. *Image: Journal of Nursing Scholarship*, 30, 63-69.
- Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: the caregiver health effects study. *Journal of the American Medical Association*, 282, 2215-2219.
- Scott, D.W., Oberst, M.T., & Dropkin, M.J. (1980). A stress-coping model. *Advanced Nursing Science*, 3, 9-23.
- Scott, G. (2001). A study of family carers of people with life-threatening illness 2: implications of the needs assessment. *International Journal of Palliative Nursing*, 7, 323-330.
- Scott, G., Whyler, N., & Grant, G. (2001). A study of family carers of people with a life-threatening illness 1: the carers' needs analysis. *International Journal of Palliative Care Nursing*, 7, 290-297.
- Sela, R. A., Watanabe, S., & Nekolaichuk, C. L. (2005). Sleep disturbances in palliative cancer patients attending a pain and symptom control clinic. *Palliative and Supportive Care*, 3, 23-31.
- Sephton, S. E., Sapolsky, R. M., Kraemer, H. C., & Spiegel, D. (2000). Diurnal cortisol rhythm as a predictor of breast cancer survival. *Journal of the National Cancer Institute* 2, 994-1000.

- Sharafkhaneh, A., & Hirshkowitz, M. (2003). Contextual factors and perceived self-reported sleepiness: a preliminary report. *Sleep Medicine, 4*, 327-331.
- Sheely, L. C. (1996). Sleep disturbances in hospitalized patients with cancer. *Oncology Nursing Forum, 23*, 109-111.
- Stajduhar, K. I. (2002). *The idealization of dying at home: the social context of home-based palliative caregiving*. University of Victoria: British Columbia Medical Services Foundation.
- Stajduhar, K. I. (2003). Examining the perspectives of family members involved in the delivery of palliative care at home. *Journal of Palliative Care, 19*, 27-35.
- Strauss, A. L. (1987). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. London: Sage Publications.
- Streubert Speziale, H. J., & Carpenter, D. R. (2007). *Qualitative research in nursing: Advancing the humanistic imperative* (4<sup>th</sup> ed.). Philadelphia: Lippincott Williams & Wilkins.
- Smith, M. C., Ellgring, H., & Oertel, W. H. (1997). Sleep disturbances in Parkinson's disease patients and spouses. *Journal of American Geriatric Society, 45*, 194-199.
- Steele, R. G., & Fitch, M. I. (1996). Needs of family caregivers of patients receiving home hospice care for cancer. *Oncology Nursing Forum, 23*, 823-828.
- Stepanski, E. J. (2005). Evaluating sleeplessness. In P. R. Carney, R. B. Berry, & J. D. Geyer (Eds.), *Clinical sleep disorders* (pp. 113-123). Philadelphia: Lippincott Williams & Wilkins.
- Strickland, O. L. (2005). Using existing measurement instruments. *Journal of Nursing Measurement, 2*, 3-6.
- Taras, H., & Potts-Datema, W. (2005). Sleep and student performance at school. *Journal of School Health, 75*, 248-255.
- Teel, C. S., & Press, A. N. (1999). Fatigue among elders in caregiving and noncaregiving roles. *Western Journal of Nursing Research, 21*, 498-520.
- Teno, J. M., Grunier, A., Schwartz, S., Nanda, A., & Wetle, T. (2007). Association between advance directives and quality of end-of-life care: a national study. *Journal of American Geriatrics Society, 55*, 189-194.
- Thorne, S. (2000). Data analysis in qualitative research. *Evidence Based Nursing, 3*, 68-70.
- Thorpy, M. J. (2005). Classification of sleep disorders. In M. H. Kryger, T. Roth, & W. C. Dement (Eds.), *Principles and practice of sleep medicine* (4<sup>th</sup> ed., pp. 615-625). Philadelphia: Elsevier Saunders.

- Thorpy, M. J., & Alder, C. H. (2005). Parkinson's disease and sleep. *Neurologic Clinics*, 23, 1187-1208.
- Tsukasaki, K., Kido, T., Makimoto, K., Naganuma, R., Ohno, M., & Sunaga, K. (2006). The impact of sleep interruptions on vital measurements and chronic fatigue of female caregivers providing home care in Japan. *Nursing and Health Sciences*, 8, 2-9.
- Vena, C., Parker, K. P., Allen, R., Bliwise, D. L., Jain, S., & Kimble, L. (2006). Sleep-wake disturbances and quality of life in patients with advanced lung cancer. *Oncology Nursing Forum*, 33, 761-769.
- Walker, L. O., & Avant, K. C. (2005). *Strategies for theory construction in nursing* (4<sup>th</sup> ed.). Upper Saddle River, New Jersey: Pearson Education Inc.
- Waltz, C. F., Strickland, O. L., & Lenz, E. R. (2005). *Measurement in nursing and health research* (3<sup>rd</sup> ed.). New York: Springer Publishing Company, Inc.
- Wilcox, S., & King, A. C. (1999). Sleep complaints in older women who are family caregivers. *Journal of Gerontology*, 54B, 189-198.
- Williams, A. M. (2004). Shaping the practice of home care: critical case studies of the significance of the meaning of home. *International Journal of Palliative Nursing*, 10, 333-342.
- Williams, A. M., Crooks, V. A., Stadjuhar, K. I., Allan, D., & Cohen, S. R. (2006). Canada's Compassionate Care Benefit: Views of family caregivers in chronic illness. *International Journal of Palliative Nursing*, 12, 438-445.
- Williamson, G. R. (2005). Illustrating triangulation in mixed-methods nursing research. *Nurse Research*, 12, 7-18.
- Willette-Murphy, K., Todero, C., & Yeaworth, R. (2006). Mental health and sleep of older wife caregiver's for spouses with Alzheimer's Disease and related disorders. *Issues in Mental Health Nursing*, 27, 837-852.
- Zammit, G. K., Weiner, J., Damato, N., Sillup, G. P., & McMillan, C. A. (1999). Quality of life in people with insomnia. *Sleep*, 22, s379-s385.

## Appendix A

### University of Manitoba Approval Certificate



UNIVERSITY  
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#### APPROVAL CERTIFICATE

08 January 2007

**TO:** N. Brenda Hearson (Advisor S. McClement)  
Principal Investigator

**FROM:** Stan Straw, Chair  
Education/Nursing Research Ethics Board (ENREB)

**Re:** Protocol #E2006:110  
"Sleep Disturbance in Family Caregivers of Community Dwelling  
Advanced Cancer Patients"

Please be advised that your above-referenced protocol has received human ethics approval by the **Education/Nursing Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

**Please note:**

- if you have funds pending human ethics approval, the auditor requires that you submit a copy of this Approval Certificate to Kathryn Bartmanovich, Research Grants & Contract Services (fax 261-0325), including the Sponsor name, before your account can be opened.
- if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.

The Research Ethics Board requests a final report for your study (available at: [http://umanitoba.ca/research/ors/ethics/ors\\_ethics\\_human\\_REB\\_forms\\_guidelines.html](http://umanitoba.ca/research/ors/ethics/ors_ethics_human_REB_forms_guidelines.html)) in order to be in compliance with Tri-Council Guidelines.

*Bringing Research to Life*

## Appendix B

### WRHA Access Approval



Winnipeg Regional Health Authority  
*Caring for Health*  
 Office régional de la santé de Winnipeg  
*À l'écoute de notre santé*

1800 - 155 Carlton St.  
 Winnipeg, Manitoba  
 R3C 4Y1 CANADA  
 TEL: 204/926.7000  
 FAX: 204/926.7007  
 www.wrha.mb.ca

155, rue Carlton, suite 1800  
 Winnipeg, Manitoba  
 R3C 4Y1 CANADA  
 TÉL: 204/926.7000  
 TÉLÉC: 204/926.7007  
 www.wrha.mb.ca

January 10, 2007

Brenda Hearson  
 10 Doral Way  
 Headingley, MB R4H 1J4

Dear Ms. Hearson,

Re: **Proposal "Sleep Disturbance in Family Caregivers of Community-Dwelling Advanced Cancer Patients"**  
 WRHA Reference No: 2006-020

We are pleased to inform you that your research access request for the above-named study has been approved by the Winnipeg Regional Health Authority (WRHA) Research Review Committee pending confirmation that the following conditions are met or agreed to:

- You, your co-investigators, and your research assistants comply with the relevant privacy legislation as indicated below.
  - The Personal Health Information Act*
  - The Freedom of Information and Protection of Privacy Act*
  - The Personal Health Information Act and The Freedom of Information and Protection of Privacy Act*
- You complete and return the attached Confidentiality Agreement(s) to Cathy Pope, WRHA, 1800 – 155 Carlton Street, Winnipeg, MB R3C 4Y1;
- You submit to our attention any significant changes in your proposal prior to implementation or any significant changes during the course of the study;
- You submit a summary of the final results of the study to the WRHA and provide us with a copy of any publications arising from the study;
- It is an expected courtesy that WRHA will be given a minimum of five working days advance notice of publication or presentation of results with policy implications. In order to be prepared for public response;
- You agree to be accountable for appropriate storage and elimination of material.

Thank you for selecting the Winnipeg Regional Health Authority as the site to conduct your research. Please let us know should you encounter any site-related difficulties during the course of your study.

We extend best wishes for successful completion of your study.

Sincerely,

Dr. Mike Moffatt  
 Executive Director, Division of Research & Applied Learning  
 Chair, Research Review Committee  
 Winnipeg Regional Health Authority

cc. Dr. B. Postl  
 Ms. L. Esposito  
 Chair, HREB

Encl: *FIPPA Agreement*

**Appendix C**  
**IRHA Access Approval**

**Brenda Hearson**

---

**From:** Doreen Fey [DFey@irha.mb.ca]  
**Sent:** January 19, 2007 1:20 PM  
**To:** Brenda Hearson  
**CC:** Shannon Pyziak  
**Subject:** Research

Hi

I am pleased to let you know that the Board of Directors approved the research study, so please go ahead. I would appreciate an update of the progress occasionally and a final report

Thanks again and good luck in your project

*Doreen Fey*

Vice President Planning  
Interlake Regional Health Authority  
ph. (204) 467-4748  
fax. (204) 467-4750  
dfey@irha.mb.ca

## Appendix D

### Initial Contact Script for Palliative Care Coordinators (Recruiters)

There is an opportunity for you to participate in a research study that is looking at the changes in your sleep and rest while caring for \_\_\_\_\_ (insert patient's name).

Brenda Hearson is a nurse who is doing this study for her Masters of Nursing degree and she is looking for people who are currently caring for someone with advanced cancer who is living in the community. Brenda is willing to explain her project to you, if you are interested. This does not mean you have to participate, she will explain the project further and you can decide if it is something you would like to take part in.

.....

Would it be okay for me to give your name and phone number to Brenda so she can contact you?

If yes, please fill out the information below:

Name: \_\_\_\_\_

Phone: \_\_\_\_\_

Brenda will contact you in the next few days.

If no, thank the person for their time and conclude the call.

Recruiters: Please call Brenda at \_\_\_\_\_ or email her at \_\_\_\_\_ to let her know if there is another interested participant.

## Appendix E



UNIVERSITY  
OF MANITOBA

### Information and Consent Form

**Research Project Title:** Sleep Disturbance in Family Caregivers of Community-Dwelling Advanced Cancer Patients

**Researcher:** Brenda Hearson, R.N., B.N., CHPCN(C)

\*\*\*\*\*  
This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.  
\*\*\*\*\*

1. This research study will focus on:
  - understanding and describing the experience of sleep disturbance while providing care to a friend or relative who is living in the community with advanced cancer,
  - exploring the most helpful ways to promote sleep and rest of family caregivers.

We know that sleep is very important to maintain our health, well-being and ability to function from day-to-day. Little research has been done to understand sleep disturbance experienced by family caregivers who are caring for patients with advanced cancer, even though we know these patients often have complex, round-the-clock care needs. I am conducting this research as part of my Masters of Nursing degree at the University of Manitoba. It is hoped that what is learned in this study will help nurses and other health care providers improve care and services offered to advanced cancer patients and their family caregivers. The member's of my thesis committee are Dr. Susan McClement, Dr. Michael Harlos, and Dr. Diana McMillan.

2. In doing this research I will be interviewing individuals in the Interlake Health Region and the Winnipeg Health Region who are currently caring for a friend or

family member who has advanced cancer and is being cared for in the community. This research will consist of two parts:

- an interview
- wearing an Actiwatch and recording a brief sleep log for 72 hours

You may participate in the interview portion even if you do not wish to wear the Actiwatch and record the sleep log.

If you agree to participate, the first visit will last approximately 1 - 1 1/2 hour. Initially I will ask questions from three brief questionnaires which gather basic information about your situation, your sleep patterns and how rested you feel during the day. I will then ask you to describe how being a caregiver has changed your sleep and rest patterns. I will also explore if you have suggestions or ideas of what might be most helpful to promote your sleep and rest. If you are agreeable, the interview will be audio-recorded. After the visit, the audio-recording of the interview will be typed out.

After the interview, you will be asked to wear a Actiwatch, which looks like a small black sports watch. This Actiwatch measures your rest and activity patterns. While you are wearing the Actiwatch, you will be asked to keep a brief sleep log, which notes such details such as what time you go to bed, what time you get up in the morning, how many times you are up in the night, how rested you feel in the morning, and nap times.

If you agree to wear the Actiwatch and record the sleep log, the research nurse will take a few moments to explain both to you and provide an instruction sheet. The research nurse will telephone the day following the visit to ask if you have any questions or concerns. The nurse will arrange a brief visit to pick up the Actiwatch and the sleep log in 3-5 days. It is estimated that it will take you no more than 10 minutes of your time per day to record the sleep log. The second visit will be less than 15 minutes.

3. No risk or harm is anticipated by participation in this research study. During the interview, if the caregiver should have more immediate concerns arise, the research nurse will set aside her research to focus on the caregivers immediate needs. Together, the research nurse and caregiver will decide if further follow-up is required and whether the family caregiver will call the Palliative Care Coordinator directly or give permission to the research nurse to call the Palliative Care Coordinator on his or her behalf.
4. The interview and follow-up visit to pick up the Actiwatch and sleep log will be arranged at a time and place that is good for you. It would be preferred to meet in your home, but should this pose a problem we can meet at a health care facility near you. In this case, I will pay for your travel costs to the meeting (rate used by the health region).

5. All information will be kept anonymous and confidential. To maintain the anonymity of the participants, each person participating in the study will be assigned a unique code number. That code number will appear on all the data collected from the individual, not his or her name. The researcher will keep a master list linking the participants' names and their code numbers in a locked drawer in her home office and separate from consent forms and raw data.

The interviews, when transcribed, will not contain any names or other identifying information. Rather any such information will be replaced by pseudonyms. The researcher will hold in confidence all information shared by participants, except that which she is legally bound to report.

Data that is presented will not contain any names or other identifying information about participants, and will be presented in aggregate form. Direct quotations may be used in reporting the data but will be used anonymously. Protecting the anonymity and confidentiality of the participants, the findings of this study will be shared in a summary report to interested participants, the regional health authorities, and the university, as well as through educational presentations at conferences and written articles for health-related journals and newsletters.

All data and research materials will be stored in a locked filing cabinet in the researcher's office. Interview data will be stored on the researcher's computer which only she can access. The Actiwatch data will be anonymously coded, downloaded, and stored using the computer/Actiware software which is kept in the locked office of Dr Diana McMillan, Faculty of Nursing (Internal Member of Thesis Committee); the research nurse and Dr McMillan will have exclusive access to the data using a specific computer access code. All study data will be kept secure for a period of seven years after which time it will be destroyed and treated as confidential waste.

6. Once the study is complete, a summary of the results will be mailed to the participants who indicate at the bottom of this consent form that they wish to receive a copy and provide their mailing address. The family caregiver names will not be used in the presentation of the results.
7. No remuneration is offered to the participants, other than to cover their travel costs if the interview takes place beyond their home.
8. Participation in this study is completely voluntary. Whether you choose to be a part of this study or not, will in no way affect any care or services you are now receiving or might receive from the Interlake or Winnipeg health region. By signing this form you are agreeing to participate. However, should you at any time want to stop being in the study you may do so. No harm is anticipated by participating in this study. Should you feel uncomfortable with any questions you can choose not to answer them.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

*Should you wish to contact the researcher or her research committee the numbers are:*

*Brenda Hearson  
Nurse research – (Phone number)*

*Dr. Susan McClement  
Thesis committee chair –(Phone number)*

This research has been approved by the University of Manitoba, Education/Nursing Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 474-7122, or e-mail [margaret\\_bowman@umanitoba.ca](mailto:margaret_bowman@umanitoba.ca). A copy of this consent form has been given to you to keep for your records and reference.

The Interlake and Winnipeg Regional Health Authorities – Palliative Care Programs have approved this study.

*Thank you for your time and participation.*

.....

I, \_\_\_\_\_, agree to participate in this study regarding sleep disturbance in family caregivers of advanced cancer patients.

I have read the above information explaining the study. I am aware that participation is voluntary and I may choose not to answer certain question or withdraw from the study at any time without penalty. I give Brenda Hearson permission to use anonymous information from my interview in any educational presentations or publications that result from this study.

---

Participant's Signature

Date

---

Researcher and/or Delegate's Signature

Date

*The findings of this study will be made available once the study has been completed.  
Would you like a summary of the results mailed to you?*

*Yes*

*No*

*If 'yes' please include your mailing address:*

---

---

## Appendix F

### Demographic Data Collection Form

**Caregiver Information    Participant ID#: \_\_\_\_\_**

Address: \_\_\_\_\_

Directions to home: \_\_\_\_\_

Mailing address (if different): \_\_\_\_\_

Postal code: \_\_\_\_\_ Phone: \_\_\_\_\_

Age: \_\_\_\_\_ Gender: \_\_\_\_\_ Relationship to the patient: \_\_\_\_\_

Length of time caregiving: \_\_\_\_\_

Primary residence same as patient: Yes \_\_\_ No \_\_\_ If no, how far away? \_\_\_\_\_ (km)

Ethnicity: \_\_\_\_\_ Level of schooling completed: \_\_\_\_\_

Occupation: \_\_\_\_\_ Employment status: \_\_\_\_\_

Sources of support: \_\_\_\_\_

Overall health status: \_\_\_\_\_

#### Patient Information - Provided by the Caregiver

Age: \_\_\_\_\_ Cancer Diagnosis: \_\_\_\_\_

Date of diagnosis: \_\_\_\_\_ Reoccurrence: \_\_\_\_\_

Activity level: \_\_\_\_\_

(Palliative Performance Scale Score based on above : \_\_\_\_\_)

#### Sleeping Arrangement

With patient?: \_\_\_\_\_ Same room?: \_\_\_\_\_

Noise (equipment?): \_\_\_\_\_

Change in sleeping arrangements since patient's diagnosis: \_\_\_\_\_

## Appendix G

### Epworth Sleepiness Scale

Participant ID#: \_\_\_\_\_ Today's date: \_\_\_\_\_

Your age (Yrs): \_\_\_\_\_ Your sex (Male = M, Female = F): \_\_\_\_\_

How likely are you to doze off or fall asleep in the following situations, in contrast to feeling just tired?

This refers to your usual way of life in recent times.

Even if you haven't done some of these things recently try to work out how they would have affected you.

Use the following scale to choose the **most appropriate number** for each situation:

- 0 = would **never** doze
- 1 = **slight chance** of dozing
- 2 = **moderate chance** of dozing
- 3 = **high chance** of dozing

*It is important that you answer each question as best you can.*

<b>Situation</b>	<b>Chance of Dozing (0-3)</b>
Sitting and reading _____	_____
Watching TV _____	_____
Sitting, inactive in a public place (e.g. a theatre or a meeting) _____	_____
As a passenger in a car for an hour without a break _____	_____
Lying down to rest in the afternoon when circumstances permit _____	_____
Sitting and talking to someone _____	_____
Sitting quietly after a lunch without alcohol _____	_____
In a car, while stopped for a few minutes in the traffic _____	_____

***THANK YOU FOR YOUR COOPERATION***

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## Appendix H

### © Pittsburgh Sleep Quality Index (PSQI)

Participant ID# \_\_\_\_\_ Date \_\_\_\_\_ Time \_\_\_\_\_ AM or PM

#### INSTRUCTIONS:

The following questions relate to your usual sleep habits during the past month only. Your answers should indicate the most accurate reply for the majority of days and nights in the past month. Please answer all questions.

1. During the past month, what time have you usually gone to bed at night?

BED TIME \_\_\_\_\_

2. During the past month, how long (in minutes) has it usually taken you to fall asleep each night?

NUMBER OF MINUTES \_\_\_\_\_

3. During the past month, what time have you usually gotten up in the morning?

GETTING UP TIME \_\_\_\_\_

4. During the past month, how many hours of actual sleep did you get at night? (This may be different than the number of hours you spent in bed.)

HOURS OF SLEEP PER NIGHT \_\_\_\_\_

***For each of the remaining questions, check the one best response. Please answer all questions.***

5. During the past month, how often have you had trouble sleeping because you . . .

- a) Cannot get to sleep within 30 minutes

Not during the past month _____	Less than once a week _____	Once or twice a week _____	Three or more times a week _____
------------------------------------	--------------------------------	-------------------------------	-------------------------------------

- b) Wake up in the middle of the night or early morning

Not during the past month _____	Less than once a week _____	Once or twice a week _____	Three or more times a week _____
------------------------------------	--------------------------------	-------------------------------	-------------------------------------

c) Have to get up to use the bathroom

Not during the past month _____	Less than once a week _____	Once or twice a week _____	Three or more times a week _____
------------------------------------	--------------------------------	-------------------------------	-------------------------------------

d) Cannot breathe comfortably

Not during the past month _____	Less than once a week _____	Once or twice a week _____	Three or more times a week _____
------------------------------------	--------------------------------	-------------------------------	-------------------------------------

e) Cough or snore loudly

Not during the past month _____	Less than once a week _____	Once or twice a week _____	Three or more times a week _____
------------------------------------	--------------------------------	-------------------------------	-------------------------------------

f) Feel too cold

Not during the past month _____	Less than once a week _____	Once or twice a week _____	Three or more times a week _____
------------------------------------	--------------------------------	-------------------------------	-------------------------------------

g) Feel too hot

Not during the past month _____	Less than once a week _____	Once or twice a week _____	Three or more times a week _____
------------------------------------	--------------------------------	-------------------------------	-------------------------------------

h) Had bad dreams

Not during the past month _____	Less than once a week _____	Once or twice a week _____	Three or more times a week _____
------------------------------------	--------------------------------	-------------------------------	-------------------------------------

i) Have pain

Not during the past month _____	Less than once a week _____	Once or twice a week _____	Three or more times a week _____
------------------------------------	--------------------------------	-------------------------------	-------------------------------------

j) Other reason(s), please describe \_\_\_\_\_

---

How often during the past month have you had trouble sleeping because of this?

Not during the past month _____	Less than once a week _____	Once or twice a week _____	Three or more times a week _____
------------------------------------	--------------------------------	-------------------------------	-------------------------------------

6. During the past month, how would you rate your sleep quality overall?
- Very good \_\_\_\_\_
- Fairly good \_\_\_\_\_
- Fairly bad \_\_\_\_\_
- Very bad \_\_\_\_\_
7. During the past month, how often have you taken medicine to help you sleep (prescribed or "over the counter")?
- |                                    |                                |                               |                                     |
|------------------------------------|--------------------------------|-------------------------------|-------------------------------------|
| Not during the<br>past month _____ | Less than<br>once a week _____ | Once or twice<br>a week _____ | Three or more<br>times a week _____ |
|------------------------------------|--------------------------------|-------------------------------|-------------------------------------|
8. During the past month, how often have you had trouble staying awake while driving, eating meals, or engaging in social activity?
- |                                    |                                |                               |                                     |
|------------------------------------|--------------------------------|-------------------------------|-------------------------------------|
| Not during the<br>past month _____ | Less than<br>once a week _____ | Once or twice<br>a week _____ | Three or more<br>times a week _____ |
|------------------------------------|--------------------------------|-------------------------------|-------------------------------------|
9. During the past month, how much of a problem has it been for you to keep up enough enthusiasm to get things done?
- |                            |       |
|----------------------------|-------|
| No problem at all          | _____ |
| Only a very slight problem | _____ |
| Somewhat of a problem      | _____ |
| A very big problem         | _____ |
10. Do you have a bed partner or room mate?
- |  |       |
|--|-------|
| No bed partner or room mate            | _____ |
| Partner/room mate in other room        | _____ |
| Partner in same room, but not same bed | _____ |
| Partner in same bed                    | _____ |

If you have a room mate or bed partner, ask him/her how often in the past month you have had . . .

a) Loud snoring

Not during the past month _____	Less than once a week _____	Once or twice a week _____	Three or more times a week _____
------------------------------------	--------------------------------	-------------------------------	-------------------------------------

b) Long pauses between breaths while asleep

Not during the past month _____	Less than once a week _____	Once or twice a week _____	Three or more times a week _____
------------------------------------	--------------------------------	-------------------------------	-------------------------------------

c) Legs twitching or jerking while you sleep

Not during the past month _____	Less than once a week _____	Once or twice a week _____	Three or more times a week _____
------------------------------------	--------------------------------	-------------------------------	-------------------------------------

d) Episodes of disorientation or confusion during sleep

Not during the past month _____	Less than once a week _____	Once or twice a week _____	Three or more times a week _____
------------------------------------	--------------------------------	-------------------------------	-------------------------------------

e) Other restlessness while you are sleeping; please describe:

---

Not during the past month _____	Less than once a week _____	Once or twice a week _____	Three or more times a week _____
------------------------------------	--------------------------------	-------------------------------	-------------------------------------

*Buyse DJ, Reynolds CF, Monk TH, Berman SR, Kupfer DJ: Psychiatry Research, 28:193-213, 1989.*

lmw:F5.PSQ (4/2002) Permission granted by Dr Buysee, October, 2006 per email.

## Appendix I

### Semi-Structured Interview Guide

1) I am interested in learning from family caregivers like yourself, how caregiving affects your ability to be able to sleep and rest. Can you tell me a bit about that, based on your experience caring for your (insert appropriate designation husband, wife, daughter, etc.)

- Probes: Could you please tell me about how your sleep/rest has changed over the course of his/her illness?
- Or from the point in time that it really seemed to change for you?
- Or over the last one or two weeks?

2) Can you tell me about what makes your sleep different or difficult?

- Probe: Recurring thoughts? What about?(e.g. personal health concerns, worry about patient, finances, etc)
- Probe: Actions taken during the day to help increase alertness? (e.g. Are you drinking more coffee?)
- Probe: Environmental factors (sleeping arrangements, etc)
- Can you think of anything else?

3) What are some of the consequences that you see as a result of your changed sleep/rest? Probes: On daily living? On your health? On your sense of well-being? On your daytime sleepiness?

4) Are there things that you would be able to do differently in providing care to your family member if you felt better rested?

5) I would now like to shift the conversation to consider the things that help to improve your sleep and rest? Probes:

- I am wondering if you have talked to your doctor, visiting nurse, or someone else about your difficulty sleeping? Could you help me to understand the reasons why you were able to do so? Or ...you were not able to do so?
- What have you done that seems to help you sleep?
- How did you learn about this method? (e.g. trial and error, from a physician, friend, etc).
- When did you start using this method?
- Are there services/resources you have used or things that you/your family do - that you have found helpful?
- If the palliative care program could offer additional help with respect to issues of sleep and rest, what suggestions do you have about what that help might be?

*For all the above questions, reinforcing signals and verbal probes such as "Can you tell me more about that?" will be used to encourage the participant to share information.*

6) Is there anything you would like to add to our conversation that I have not asked you about?

7) The Actiwatch will be shown to the caregiver, with a brief explanation of how to use it and expectations while wearing the watch (leave on at all times except when showering, bathing or playing contact sports, press the event button 2-3 times for any event [e.g. when turn out the light to go to bed], and record a brief sleep log [show them a copy of the sleep log]). Then ask the caregiver... Would you be willing to wear an Actiwatch which measures your rest and activity patterns over the next three days? Would you be willing to fill in a brief sleep log while wearing the watch? If so, I will provide you with further information on how to use the watch and record the sleep log and leave an instruction sheet with you.

If they decline 7) and a reason was not already offered, explore this further if possible:

8) I respect that you are choosing not to wear the Actiwatch. Is it possible to tell me why you are choosing not to do so? (e.g. perhaps that you feel that you already have too many things to keep track of ?)

**Thank you**

**Appendix J****Sleep Log**

**Brenda Hearson, RN, BN  
University of Manitoba  
Faculty of Nursing  
Phone**

**Actiwatch****Time On:** \_\_\_\_\_**Time Off:** \_\_\_\_\_**Wearing on: R or L**

**Acknowledgement: This Sleep Log was developed by Patricia Carter, RN, PhD, University of Texas at Austin School of Nursing, and is used with her permission for this research project (granted October 2006).**

PARTICIPANT ID # \_\_\_\_\_

Please record the following information for ***each day*** you are wearing the Actiwatch®.

1. **Day one** \_\_\_\_\_ (date) Over night respite: Yes \_\_\_\_ or No \_\_\_\_
2. Time to bed: \_\_\_\_\_ am pm (circle one)
3. Time out of bed: \_\_\_\_\_ am pm (circle one)
4. My sleep was interrupted last night (circle one)  
     No                                  Yes                                  If Yes, how many times \_\_\_\_\_
5. How long did it take you to get back to sleep after being wakened? \_\_\_\_\_
6. My sleep was interrupted because: (mark all that apply)
 

a. I needed to go to the bathroom	Y	N
b. The room temperature was too HOT/COLD	Y	N
c. I had too many thoughts running through my mind (Worry?)	Y	N
d. There was too much noise in the house	Y	N
e. I was restless, I tossed and turned	Y	N
f. I had physical pain		
g. My spouse (person with cancer) needed me to do something for them (circle all that apply)	Y	N
1. Medication	Y	N
2. Medical equipment care (e.g., Catheter, drains, IV or other pumps)	Y	N
3. Help to move in bed	Y	N
4. Nausea/vomiting	Y	N
5. Incontinence (loss of control of bowel or bladder)	Y	N
6. Help to the bathroom		
7. Other reasons my sleep was interrupted: (please explain)
 

---



---



---
8. How would you rate your sleep for this night?
 

1. Very Good	2. Fairly Good	3. OK	4. Fairly Bad	5. Very Bad
--------------	----------------	-------	---------------	-------------
9. How does this compare to your “normal” sleep experiences?
 

1. Exactly the same	2. Somewhat worse	3. Somewhat better
---------------------	-------------------	--------------------

**10. THE DAY AFTER:**

- a. Briefly describe your energy level, sleepiness, fatigue, mood, ability to get your work done.

11. Did you take a nap? (circle one)            No            Yes

**If yes:** What time of day did you nap? \_\_\_\_\_ am pm (circle one)  
 How long was your nap? \_\_\_\_\_ minutes hours (circle one)

**Removal of Actiwatch®**

Date	Reason	Time removed	Time replaced

**PLEASE CONTINUE**

**10. THE DAY AFTER:**

- b. Briefly describe your energy level, sleepiness, fatigue, mood, ability to get your work done.

11. Did you take a nap? (circle one)            No            Yes

**If yes:** What time of day did you nap? \_\_\_\_\_ am pm (circle one)  
 How long was your nap? \_\_\_\_\_ minutes hours (circle one)

**Removal of Actiwatch®**

Date	Reason	Time removed	Time replaced

**PLEASE CONTINUE**



**10. THE DAY AFTER:**

- c. Briefly describe your energy level, sleepiness, fatigue, mood, ability to get your work done.

11. Did you take a nap? (circle one)            No            Yes

**If yes:** What time of day did you nap? \_\_\_\_\_ am pm (circle one)  
 How long was your nap? \_\_\_\_\_ minutes hours (circle one)

**Removal of Actiwatch®**

Date	Reason	Time removed	Time replaced

**THANK YOU FOR YOUR PARTICIPATION IN THIS STUDY**

## Appendix K

### Instructions for Use of Actiwatch®

Master of Nursing Research Thesis by Brenda Hearson  
*Sleep Disturbance in Family Caregivers  
of Community-Dwelling Advanced Cancer Patients*

-Please wear on your non-dominant wrist. In other words if you are right-handed, please wear it on your left wrist.

- Secure it so it is snug but not uncomfortable for you

-Wear it all day and all night

-Remove only for taking a shower, a bath, or playing contact sports

-Press the event button on the front of your Actiwatch two or three times in a row to indicate the following events:

- when you turn out the lights to go to sleep
- when you get out of bed in the morning
- when you get up in the night, such as going to the bathroom or assisting someone
- when you go back to bed after going to the bathroom or assisting someone
- when you take the Actiwatch off to have a bath or shower or for contact sports
- when you put it the Actiwatch back on after your bath, shower or sports event

Important: Do not worry if you forget to push the button, just continue to do so to mark events as much as often as you can remember

Thank you for wearing the Actiwatch®

If questions or concerns, call Brenda Hearson, Research Nurse @ (Phone number was provided)