Title
Sleep disturbances in gastric cancer patients and their family caregivers

Author
Cho, Maria H

Publication Date
2004

Sleep Disturbances in Gastric Cancer Patients and Their Family Caregivers

by

Maria H. Cho

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

Physiological Nursing

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

[redacted]

Date University Librarian

Degree Conferred: ....

Acknowledgement

"Life is not an accident; it was planned by God all along"

I came to the States on Dec 15, 1994, right after my 27th birthday, with my husband, Joshua, and Elizabeth (in my tummy), because my mother wanted to make a special birthday dinner table for me to wish for long life and good luck in America. Now, I have been here almost 10 years. When I think back on my time in the States, I am sometimes overwhelmed by waves of emotion, sometimes joyful, often times sorrowful, many times heartbreaking, and I remember being poor for a long time. However, it is all covered by feeling extraordinarily privileged and blessed to have been a nursing doctoral student in University of California at San Francisco over the last four years.

I began my nursing career without knowing the meaning of nursing, but this has been changed tremendously since the beginning of my life at UCSF. Life is not an accident; it has been planned by God all along. If I wanted to reach the stars by myself, it couldn't be accomplished, but being in this enriching environment with brilliant people who encourage and support me has made it possible. I am truly blessed to have my committee members and faculty, who have not only imparted their knowledge but have also been open, warm, and culturally sensitive.

First and foremost, I am deeply grateful to Marylin who is more than a mentor. Without you, I would not be here. You treated me and my family as if we were your own family-bringing gifts for my kids every time you went abroad, sending greeting cards for all occasions, inviting us to your home for dinner, and helping my finances by writing many reference letters for me to apply for scholarships. But most importantly, I've seen your passion for the science of nursing. Your endless love of nursing and belief in nursing science has made a difference in nursing practice. This has molded and shaped my thoughts of nursing in totally different ways, and finally, led me to say "I want to be a nursing scientist that makes a difference in everyday life for the cancer patient".

Kathryn A Lee, my qualifying exam chair and committee member, the best I've ever had. I am so fortunate to have learned from you, not just about sleep, but about being a nurse sleep scientist. Your constant encouragement and untiring positivity was instrumental in getting me though this. The more I learn from you, the better I understand exactly how brilliant you are.

Geraldine Padilla, committee member, always gave me great comments and thoughtful suggestions when thinking about cultural aspects. Your suggestions for the quality of life instrument for Korean gastric cancer patients and their family caregivers provided valuable perspectives to this research, providing a very rich and productive dissertation experience.

Rob Slaughter, who told me "writing a dissertation is like a rite of passage" which was truly true. Every time I had questions about the instruments, you transformed the big words to simple understandable words which made it easy for me to understand. Your comments and thoughts about the instruments were not just great, but more importantly, made me think about asking the right questions to get the right answers.

Lastly but most certainly not least, I would like to thank Karla Lindgren, my editor who spent time reading, discussing, writing and rewriting with me over my doctoral program. I am so thankful because of your patience and efforts to understand my broken sentences. Anne Huges, who is gentle as a spring breeze, always supporting and encouraging me. Steven Paul and Bruce Cooper, two mighty statisticians, helped me to understand the meaning of numbers in the output of SPSS. I also deeply thankful to Sang Hong Lee, RN and the Asan Medical Center Nursing department who helped me to recruit the study participants in a very short period of time. I also would like to thank the Korean gastric cancer patients and their family caregivers who volunteered to be a part of this study. Finally, my beloved Pistos church members who prayed for me every time when I desperately needed it.

Maria H. Cho
11 May, 2004

Sleep Disturbances in Gastric Cancer Patients and Their Family Caregivers

Maria H. Cho
University of California, San Francisco, 2004

Purposes: The purposes of this study are to: (a) describe sleep patterns and characteristics in gastric cancer patients who are receiving chemotherapy and their family caregivers, (b) describe the group and gender differences of sleep characteristics in patients and family caregivers, (c) describe the relationships between other symptoms and sleep disturbances in cancer patients and their caregivers, (d) describe the important predictors of cancer patients and their family caregivers' quality of life.

Theoretical Framework: Symptom Management Model

Sample: A paired sample of gastric cancer patients who are receiving chemotherapy and their family caregivers (N=103) participated.

Study Design: Descriptive, Cross-Sectional study design

Measurements: Demographic profiles, Pittsburgh Sleep Quality Index (PSQI), Sleep Diary, Center for Epidemiological Studies of Depression (CES-D), Lee Fatigue Scale (LFS), Brief Pain Inventory (BPI), and Quality of Life-Cancer (QOL-CA) were used.

Data Analysis: Descriptive Statistics, Matched Paired t-test, Independent t-test, multiple regressions.

Results: Mean ages of sample were 52.29 (SD 10.07) for patients and 48.25 (SD 11.37) for family caregivers. More than 84% of the caregivers were the spouses of the patients, and 10.7% of caregivers were either the daughter or daughter-in-law, 87% of caregivers were female. Global PSQI was 6.92 (SD=1.45), mean falling asleep time was 22.96 minutes (SD=19.98) and average hours of sleep was 6.74 hours (SD=1.45). More than 50% of patients and family caregivers had sleep disturbance, which is moderately correlated with depression in both groups. Sleep and fatigue were not correlated in patients' group, but moderately correlated in family caregivers' ($r=0.32$, $p<0.01$). There were gender differences in each group for depression and fatigue, but not in quality of life and global sleep quality. Approximately 43% of variance in quality of life was explained by selected demographic variables (financial status, health status) and symptoms in patients and family caregivers. In both patients and caregivers, depression was the largest unique contribution to variance in quality of life.

Conclusions: Korean gastric cancer patients and their family caregivers had sleep disturbance, which is related to other co-existing symptoms such as depression and fatigue. Further study is needed to explicate correlations between objective and subjective measures of sleep, why sleep is poorly correlated with fatigue in patients and whether early recognition and treatment of depression affects sleep disturbance.

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CHAPTER I

THE STUDY PROBLEM

Introduction

Sleep is a universal need of all human beings (Aldrich, 1999; Hodgson, 1991; Lee, 1997; Parker, 1995). A certain amount of sleep is necessary to sustain a productive daily lifestyle (Oswald, 1980; Sheely, 1996). The benefits of sleep are the restoration and recovery of biochemical and physiological processes, which are progressively degraded during prior wakefulness (Hodgson, 1991; Roehrs, 2000). The quality and quantity of sleep may significantly affect health and quality of life. Adequate sleep yields positive outcomes characterized by short sleep latency, a long period of continuous sleep with minimal body movement, and a sense of feeling rested after awakening (Knab & Engel-Sittenfeld, 1983). In contrast, poor sleep can lead to negative outcomes such as mood changes, increased fatigability, irritability and aggressiveness, decreased tolerance for pain, weight loss, increased energy expenditure, glucose intolerance, a weakened immune system, and a reduction of natural killer cell activity (Dinges et al., 1994; Hodgson, 1991; Irwin, Smith, & Gillin, 1992; Pace-Schott & Hobson, 2002; Thomas, 1987). In addition, sleep deprivation drives down growth hormone production, which controls the body's proportion of adipose tissue and lean muscle (Van Cauter & Copinschi, 2000).

Statement of the Problem

Patients' Perspectives: Even in healthy people, prolonged sleep disturbance due to various reasons can lead to many negative outcomes. Persons with cancer are already at high risk for experiencing inadequate sleep which results in various negative outcomes, as mentioned earlier. This negative impact can be seen in mood changes, fatigue, a decreased daytime activity level, depression, decreased pain tolerance, memory problems, decreased concentration, poor coordination, increased mortality, and poor quality of life (Asplund, 1999; Beszterczey & Lipowski, 1977; Chuman, 1983; Kripke, Garfinkel, Wingard, Klauber, & Marler, 2002; Mormont et al., 2000; Weitzman et al, 1974). In addition, having sleep disturbances that change or disrupt cancer patients' individual circadian rhythms of biological processes (Ancoli-Israel, Moore, & Jones, 2001) may possibly affect quality of life, survival rates and treatment outcomes (Kripke, Garfinkel Wingard, Klauber, & Marler, 2002; Mormont et al., 2000).

The prevalence of sleep disturbance in cancer patients is as high as 95% depending on cancer type, stage, treatment, age, gender, and environment (Ginsburg, Quirt, Ginsburg, & Mackillop, 1995; Silberfarb, Hauri, Oxman, & Schnurr, 1993; Thomas, 1986; Yellen & Dyrozak, 1996). Although cancer-related sleep disturbance is common (Moore & Dimsdale, 2002; Thomas, 1987), it is relatively undocumented empirically in cancer patients and the etiology is unknown (Hu & Silberfarb, 1991; Owen, Parker, & McGuire, 1999; Savard, Simard, Blanchet, Ivers, & Morin, 2001; Silberfarb et al., 1993; Yellen & Dyonzak, 1996). Several studies have shown that sleep disturbance might be related to the cancer itself; the impact of the diagnosis; treatment-related side effects such as pain, fatigue and depression; or hospitalization (Hodgson, 1991; Miaskowski & Lee, 1999; Sheely, 1996; Thomas, 1987; Yellen & Dyonzak, 1996). However, results from studies of the relationships between sleep disturbances and related factors are inconsistent (Beszterczey & Lipowski, 1977; Engstrom, Strohl, Rose, Lewandowski, & Stefaneket, 1999; Kaye, Kaye, & Madow, 1983; Owen et al., 1999).

Family Caregivers' Perspectives: Cancer is not only a life threatening situation for the patient, but the anguish that results from a diagnosis of cancer also extends to each family member (Bloom, 2000; Gotay, 2000; Yates, 1999). Nearly one out of every three families will one day be affected by cancer, which means virtually everybody can expect to be involved in at least one close relationship with someone who has cancer (Morse & Fife, 1998). Cancer is a family matter (Cooley & Moriarty, 1997). Family members often take on the active caregiver role, placing them in an unsettling and distressed situation (Schumacher, 1996), and the time from diagnosis to the terminal stage impacts on each family member in every way (Blanchard, Albrecht,

& Ruckdeschel, 1997; Morse & Fife, 1998). Caring for cancer patients is not quantifiable and is invaluable to the patient, but not without personal cost to the caregiver (Carter & Chang, 2000;Carter, 2002).

Caregivers of patients with advanced cancer experience depression and sleep problems due to the time, labor, and stress involved (Carter & Chang, 2000; Given et al., 1992). Cancer patients need constant attention from their caregiver for assistance in taking medications, hospital visits for treatment, and personal needs. For example, medication for pain control must be taken at regular intervals, thus contributing to the interruption of the caregiver's sleep cycle (Carter & Chang, 2000). As a result of being needed 24 hours a day, caregivers experience negative physical and emotional outcomes such as depression, fatigue, sleep disturbance, and low quality of life (Carter & Chang, 2000 ;Kurtz, Kurtz, Given, Given,1996). In addition, family members may lack the resources, skills, and knowledge needed to care for cancer patients, as the skills necessary for dealing with unexpected illness may not commonly be needed in every day life (Richardson, 1992).

<u>Korean Cancer Patients and Caregivers:</u> Gastric cancer is the number one cancer diagnosis in Korea (Public Health Department in Korea, 2001). The incidence of all cancer in Korea has increased 4.7% since 2002, and the total number of cancer patients was 291,820. The majority of people diagnosed with gastric cancer

receive chemotherapy as their post-surgical treatment. During chemotherapy, cancer patients may experience many unwanted side effects (Owen, Parker, & McGuire, 1999) . Sleep disturbance is one of the symptoms cancer patients experienced during the course of treatment. The health care system in Korea has been rapidly changing with a shifting of cancer care from the inpatient arena to an outpatient one. Hence, the responsibility for caring for an ill-family member has shifted to family caregivers. This can lead to progressive sleep deprivation that affects family caregivers' emotional ability to continue as caregivers as well as their quality of life.

However, not many studies have systemically looked at the effects of cancer on the family in either the United States (Lewis, Hammond, & Woods, 1993) or in Korea (Chang, 1998). Most studies have focused on individual patients rather than the family as a unit for coping, adjustment, and adaptation through the illness trajectory (Lewis, Ellison, & Wood, 1985; Gotay, 2000). In addition, both the cancer patients' and caregivers' sleep patterns (change in amount and timing of sleep within a 24-hour period of time) and characteristics (early morning awakening, frequent awakening during night) have been understudied.

Purpose of the Study

The purpose of this study was to investigate the sleep disturbance of gastric cancer patients receiving chemotherapy and their family caregivers in Korea. The following research aims were posed to

1. Describe sleep quality in gastric cancer patients receiving chemotherapy.
2. Describe sleep quality in their family caregivers.
3. Describe the gender differences in sleep quality in both patient and family caregiver.
4. Describe the relationships between sleep quality and other symptoms in cancer patients and their caregivers.
5. Describe the predictors of quality of life in cancer patients and their family caregivers.

Significance of the Problem

Sleep disturbance is a prominent complaint in cancer patients (Ancoli-Israel, Moore, Jones, 2001; Owen et al., 1999). Research related to sleep disturbance in cancer patients has been conducted mostly in the U.S. There is little research on the prevalence, etiology, or symptom presentation of Korean cancer patients with sleep disturbances. In addition, no studies could be located in Korea on the family caregiver's sleep problems. This study is unique in that it will be the first in Korea to examine sleep disturbance in both the patients with gastric cancer and their family caregivers. This study will make several important contributions to knowledge in the area: 1) to capture baseline knowledge on gastric cancer patient and family caregiver sleep patterns, characteristics, and factors that may contribute to sleep disturbances; 2) to determine the correlations between sleep disturbance, demographic variables and other symptoms in Korean cancer patients and their family caregivers; 3) to determine the importance of gender in sleep characteristics in patients and family caregivers; and 4) to describe how sleep disturbance affects the overall quality of life for cancer patients and their family caregivers. These findings may provide new and important information for clinicians and lead to improving assessment and management of sleep disturbances both for patients and family caregivers.

CHAPTER II

LITERATURE REVIEWS

Introduction

As discussed in Chapter 1, gastric cancer is the prevalent cancer in Korea and much of the caregiving is done by family members. There have been a few studies looking at sleep disturbance in cancer patients, but there have been no studies on Korean patients or caregivers. Literature reviews presented in this chapter will be organized as follows. First, prevalence of cancer in the U.S. and in Korea is reviewed including a brief description of gastric cancer and issues around family caregivers. Second, prevalence of sleep disturbance and characteristics of sleep disturbance will be described including a definition of sleep disturbance. Third, correlated factors with sleep disturbance will be reviewed based on predisposing and precipitating factors. Fourth, a conceptual framework will be described. Finally, a literature review of some studies of patients and family caregivers in the U.S. and Korea will be reviewed and critiqued.

Background

Cancer Prevalence

In the year 2004, it has been estimated that 1,368,030 new cases of cancer will be diagnosed in the U.S., and 563,700 people will die from the disease (American

Cancer Society, 2004). The American Cancer Society (ACS) estimates that one third of the population will develop cancer at some point in their life (ACS, 2001). One in four death in the U. S. is caused by cancer (Jemal et al., 2003). The incidence of cancer increases with age, with most cancers first appearing during middle age. Approximately 80% of all cancer diagnoses occur at age 55 or older (ACS, 2001).

In males, prostate cancer is the leading type followed by cancers of the lung, colon, and urinary bladder. In females, breast cancer is the number one cancer followed by cancers of the lung, colon, and uterus. Over the past ten years, mortality associated with cancer declined for both genders. Incidence rates in females increased slightly, due to an increase in breast cancer among some groups or possibly as a result of increased early detection (Howe et al., 2001). The consolidated survival rate for all cancers was 63% in 2004 (ACS, 2004), and this figure increased 4 % since 2000 (ACS, 2004).

According to the Public Health Department of Korean Reports, 291,820 patients were diagnosed with cancer in 2003. Comparing this figure to Organization for Economic Cooperation and Development (OECD) countries, the incidence of cancer is based on a population 100,000, there are 236 cancer patients in Korea which is lower than the U.S. (476), Germany (423), Italy (418), but similar to Britain (249) and Japan (205) (SEER, 2003).

Gastric Cancer Prevalence

Gastric cancer is the second leading cause of cancer death in the world and five-year survival rates are low (www.cancer.gov). Gastric cancer was the most common form of cancer in the world in the 1970s and early 80s, and has been surpassed only recently by lung cancer (Miller et al., 1996). Gastric cancer incidence rates show substantial variation internationally. Rates are highest in Korea and Eastern Asia, but generally lower in Western Europe and the U.S. In the U.S., Filipino and non Hispanic whites have substantially lower incidence rates than any other group, and even here the incidence rate for Korean men is nearly 5.8 times greater than the rate for Filipino men (Miller et al., 1996).

In Korea, gastric cancer has the highest prevalence (20%) overall, followed by lung (11.9%), liver (11.3%), colon (11.2%) and breast cancer (7.4%). One of the noticeable changes was an increasing number of breast cancers in women, although previously, gastric cancer had the highest prevalence. The main reason for the change in type of cancer and increased incidence rates for cancer in Korea might be explained by the influence of the western diet which has led to an increase in obesity (www.amdoctor.com).

Although the epidemiology of gastric cancer is multifactorial, both environmental and genetic factors are believed to contribute to the development of gastric cancer (Sawyers & Eaton, 1992). Dietary factors (exogenous environmental) that have been associated with a higher risk of gastric cancer are low ingestion of carotene, retinol, vitamin C, and raw vegetables and high ingestion of sodium, nitrates, meats, fats, and starch (Graham et al., 1990). Korean dietary preferences include hot and spicy food made with red pepper and a high salt content (fermentation food). High rates of cigarette smoking and alcohol consumption also contribute to the high incidence of gastric cancer. Further, a high prevalence of infection with helicobacter pylori of up to 91% in one study (Rhee et al., 1990), which causes chronic active gastritis is another contributing factor to this high incidence of gastric cancer in Korea.

Family Caregivers

Based on current census data in the U.S., more than 50 million people provided care for a chronically ill, disabled or aged family member or friend during the past year (National Family Caregiver Association [NFCA], 2000). The value of the services family caregivers provide without financial charge is estimated to be $257 billion a year (Arno, Levine, & Memmott, 2002). According to NFCA reports (2002), 61% of those family caregivers who provide at least 21 hours of care a week have suffered from depression. Depression is not the only problem for family caregivers, but also the consequences of sleep disturbance are pivotal in leading to many other difficulties.

By the end of 2003, It was estimated that there would be over100,000 new cases of cancer in Korea the end of 2003. With an average of four members per household, approximately 400,000 people, patients as well as family members, will be affected by cancer. In Korea, just the cost of treatment for one cancer patient for one course of chemotherapy is 3,877,000 Won (approximately $3,200) (Health Index Report 1997, survey of Seoul citizens), which is more than the average monthly salary. However, the actual cost of caring for one patient is more than 10 times that amount (www.weekly.chosun.com), because the caregiver's costs are not included.

Characteristics of Sleep Disturbances

Sleep disturbances experienced by cancer patients include awakening during the night, sleeping less than normal, having troubled dreams or nightmares, and worrying about sleep before bedtime (Engstrom et al., 1999). Another study reported that cancer patients were more likely to have difficulty with sleep onset and maintenance and early morning awakening than healthy sleepers (Hu & Silberfarb, 1991; Yellen & Dyonzak, 1996). These characteristics are the defining traits of insomnia. According to DSM-IV (Diagnostic and Statistical Manual of Mental Disorders –American Psychiatric Association, 1994), primary insomnia is characterized by difficulty initiating sleep (more than 30 minutes), difficulty maintaining sleep (more than 30 minutes of nocturnal awakening), and sleep efficiency of less than 85%. Insomniacs experience these types of sleep disturbances at least three nights per week and they exhibit significantly impaired daytime function and/or distress related to their sleep disturbance. Insomnia is the most commonly reported sleep problem in cancer patients with a prevalence ranging from 40-61% in various types of cancer patients (Hu & Silberfarb, 1991; Savard et al., 2001) and these problems sometimes last a long time.

The duration of sleep disturbances in cancer patients is important to recognize because this may indicate whether a sleep disturbance is transient, chronic, or incapacitating (Shapiro, Rodrigue, Boggs, & Robinson, 1994). Sleep disturbances in cancer patients tend to be chronic since cancer is a chronic illness, and sleep patterns may change in terms of total sleep time, sleep latency, and increasing wake time during the night. It has been suggested that the likelihood of developing insomnia may peak several times during the illness trajectory and even several years after completing adjuvant cancer treatment (Couzi, Helzlsouer, & Fetting, 1995; Harrison et al., 1997; Page, 1985; Savard et al., 2001). Cimprich (1999) reported that 88% of 65 patients experienced sleep difficulty before their cancer treatment. Several studies reported sleep disturbances during treatment (Berger & Farr, 1999; Engstrom et al., 1999; Owen et al., 1999). According to Savard et al. (2001) in their sample of breast cancer women, the median duration of insomnia symptoms was four years.

Unfortunately, compared to sleep studies in different disease populations, sleep research in cancer populations has a small body of literature and studies with family caregivers of cancer patients are even fewer. Therefore, it is hard to reach a consensus when so little is known as to whether family caregivers have sleep problems at all. However, even though this is an understudied area, two studies have strongly suggested that cancer caregivers had difficulty falling asleep, restless sleep, trouble staying sleep and also experienced non-restorative sleep (Carter 2000; Flaskerud, Carter, & Lee, 2000).

These investigators found, also, that few people used sleep medication to assist them since they were needed frequently during the night to provide care (Carter & Chang, 2000; Carter, 2002). One of the origins of the caregiver's sleep problems, according to qualitative interview findings, was the patients' own sleeping difficulties. In addition to this, caregiver's emotions such as depression or tension may be key factors in influencing their sleep problem too (Carter, 2002).

The duration of sleep disturbance in the cancer caregiver has not been studied, but Carter's (2002) qualitative report showed that all caregivers (N=47) reported some change in their sleep since their family member's diagnosis of cancer. More than 95% of the caregivers in this sample reported moderate to severe problems.

Prevalence of Sleep Disturbances

Studies show that cancer patients are at greater risk for developing insomnia and disorders of the sleep-wake cycle in comparison to a healthy control group (Malone, Harris, & Luscombe, 1994; Mormont & Levi, 1997). Sleep disturbances can appear beginning with the diagnosis of cancer and continue to the point where patients are cured from cancer. Davidson, MacLean, Brundage, & Schulze (2002) conducted a cross-sectional survey study of 982 cancer patients and found that 48% experienced insomnia at the time of diagnosis, 6 months prior to and 18 months after diagnosis. These findings suggested that there might be a high prevalence of sleep disturbances in cancer patients at any point in time.

Different cancer types and treatments may contribute to different levels of sleep problems in cancer patients. In a study of patients undergoing autologous bone marrow transplantation, 29% experienced sleep disturbances (Andrykowski, Henslee, & Farrall, 1989). Thomas (1986) found that 95% of 300 cancer outpatients experienced transient or persistent insomnia. Nail, Jones, Greene, Schipper, & Jensen (1991) found that 55% of 49 patients with various types of cancer experienced moderate to severe sleep difficulty two days after chemotherapy. Sarna (1993) studied 69 lung cancer patients and found that 31% reported insomnia. In a sample of stage I and II breast cancer patients, 23% reported insomnia for two to five years after the initiation of their cancer treatment (Lindley, Vasa, Sawyer, & Winer, 1998). Silberfarb et al. (1993) reported that 53% of patients with breast cancer and 79% of patients with lung cancer experienced insomnia. Savard et al. (2001) used a sample of 300 women with non-metastastic breast cancer who had received radiation therapy to measure the prevalence of insomnia. Forty-eight percent of these women currently had sleep difficulties and 28% of them were using sleep-aid medications. At least 40% of 52 women with ovarian and uterine cancer reported sleep disturbance as well as other symptoms (e.g., fatigue, diarrhea, and nausea) during radiation therapy (Christman, Oakley, & Cronin, 2001). The prevalence of sleep disturbances in ovarian cancer patients was 60% in all stages of the disease (Portenoy et al, 1994). Krech & Walsh (1991) studied a sample of 39 patients with un-resectable pancreatic cancer over a two-year period. They found that more than 50% of them experienced sleep disturbances.

Although the prevalence rates listed above seem high, it is difficult to determine the true prevalence of sleep disturbance in cancer patients, because few studies have described the clinical features of the problem and findings are inconsistent (Owen et al., 1999; Silberfarb et al., 1993; Yellen & Dyonzak, 1996). The prevalence of sleep disturbances in cancer patients varies depending on the type of cancer; with breast cancer ranging from 23 to 44% (Lindley et al., 1998; Silberfarb et al., 1993), lung cancer ranging from 25 to 52% (Sarna, 1993), pancreatic cancer at about 54% (Krech & Walsh, 1991), and ovarian at about 60% (Christman et al., 2001).

The reason for such large ranges relates to the different cancer types and treatment modalities. In addition, the level of sleep disturbance varies from patient to patient in association with their own individual sleep characteristics (e.g., sleep/wake cycle, circadian rhythm) and the medications used to help them sleep. Although prevalence studies have been shown to have many methodological flaws, sleep disturbance is a common problem in cancer patients (Savard et al., 2001), and increasing knowledge of the nature and prevalence of these problems will provide for new nursing approaches in supportive care for these patients (Davidson et al., 2002).

There were only five studies looking at sleep disturbance in the family caregiver of cancer patients (Carter & Chang, 2000; Carter, 2002; Carter, 2003; Flaskemd et al., 2000; Teel & Press, 1999). The sample sizes in all of them were small, ranging from 10 to 51. Three of the studies were with patients in advanced stages of cancer. The prevalence of sleep disturbance in family caregiver for these studies was up to 95%, which is similar to patients (Carter, 2002; Carter & Chang, 2000; Thomas, 1986).

Conceptual Framework

It is apparent that a variety of variables or influencing factors may be responsible for sleep disturbance in cancer patients. However, most of the previous research on sleep disturbance has not used a theoretical framework. The theoretical framework for this phenomenon includes multiple components (e.g., age, gender, menopausal status, circadian rhythm etc), but several additional components such as culture, risk factors, and socioeconomic status need to be considered as well in order to understand this phenomenon and develop interventions.

The Symptom Management Model (Figure 1) is the guide for the researcher to conceptualize the present study. Symptom Management Model (SMM) was introduced in 1994 by Larson et al.(1994). The symptom experience is the primary reason people seek health care, and nurses have traditionally focused on patients' symptoms and their management (UCSF School of Nursing, 1994). According to Dodd et al. (2001), the definition of a symptom is "a subjective experience reflecting changes in the biopsychosocial functioning sensations, or cognition of an individual."(page 669). SMM is based on the premise that effective management of any given symptom or group of symptoms demands that all three dimensions:

Symptom Experience, Symptom Management Strategies, and Outcomes related to symptom status need to be considered. The three nursing domains: Person, Health and Illness, and Environment are contextual variables influencing and surrounding all three dimensions of the symptom in the SMM. The relationships within the model are conceptualized with bi-directional arrows, which denote the mutually influential effects of the symptom.

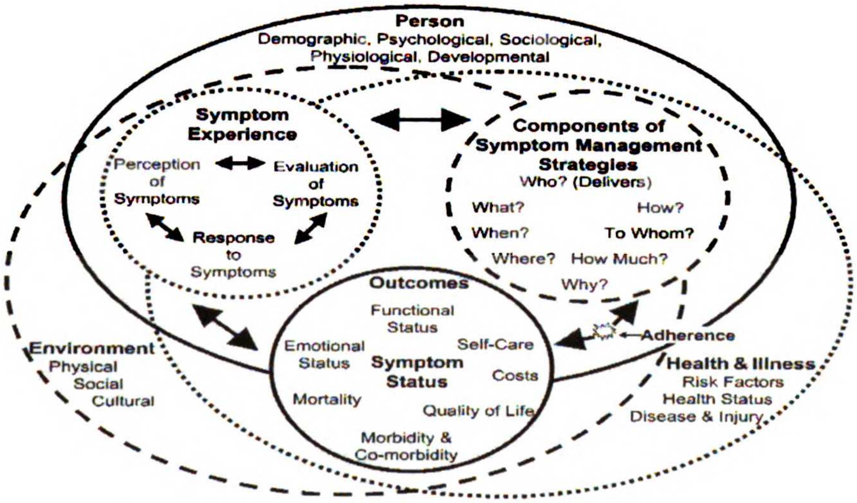


Figure 1. Symptom Management Model

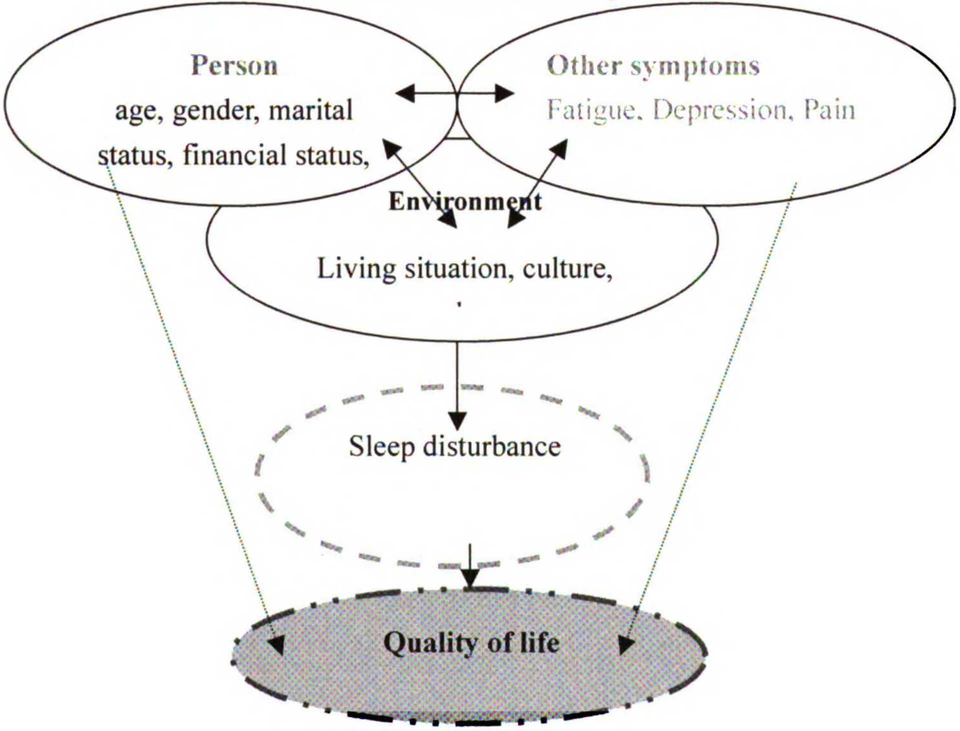
The Person domain includes demographics (e.g., age, gender, ethnicity, marital status, financial status), psychological (e.g., personal trait), sociological (e.g., family unit, culture, religion), physiological (e.g., rest-activity pattern, physical capacity), and developmental which are intrinsic to the way an individual perceives and responds to the symptom experience. The Health and Illness domain consists of risk factors (e.g., hereditary or behavioral), injury and disabilities (e.g., chronic or acute), and health status (e.g., physiological rhythm, bodily structure, and behavior). It might have direct or indirect effects on symptom experience, management and outcomes. Environment is the set of conditions or circumstances that constitute the atmosphere and background for a symptom perception. It includes physical (home, work, hospital), social (one's social support network, interpersonal relationships), and cultural factors (beliefs, values, and practices). These three domains delineate the variables that influence a person's perception and evaluation of their symptoms, management, and outcome.

The three dimensions of symptoms (experience, management, and outcomes) are based on the premise that they are dynamically interrelated. Symptom experience is the first dimension, which involves perception, evaluation and response. Perception refers to whether the individual notes a change from the way they usually feel or behave through individual conscious or cognitive interpretation of the information in a specific context. Symptom evaluation refers to the judgment of severity, intensity, location, temporal nature, frequency, and treatability of symptoms. Response refers to feeling, thoughts, or behaviors related to the health problem. This is shown through psychological, physiological and behavioral components.

The second dimension is Symptom Management Strategies, which influence not only Symptom Outcomes, but also Symptom Experience. Management starts with an assessment of the symptom experience from the patient's perspective and then focuses on implementing interventions depending on one's experience. Symptom Management Strategies include several components that answer the following questions: what type of strategy, when, where, why, how much, to whom, and how (delivered). The third dimension is Symptom Outcomes, which includes seven multi-dimensional indicators: symptom status, self-care ability, morbidity and co-morbidity, mortality, emotional status, cost, functional status and QOL. Symptom status has a central position in symptom outcome and the other indicators are related to or affect it.

Using the SMM as a guide the researcher modified this model to demonstrate sleep disturbance in cancer patients and family caregivers.

Figure 2. Conceptual Framework of Sleep Disturbance in Gastric Cancer Patients and Their Family Caregivers



Correlates of Sleep Disturbances in Cancer Patients

Although a diagnosis of cancer today may no longer be considered a death sentence, previous studies that followed patients from diagnosis to remission or recurrence have documented many kinds of emotional and physical burdens, which have triggered sleep disturbances (Akechi et al, 2001). The etiology of sleep problems in cancer patients is unknown, but hypotheses include the cancer itself, the cancer treatment or related symptoms, physiological origins (e.g., pain, fatigue), psychosocial factors (e.g., anxiety, depression) and many others (e.g., environment, medication, and socioeconomic) (Thomas, 1987; Yellen & Dyonzak, 1996). Other possible etiologies of sleep disturbance in cancer patients may include increased cytokine production during treatments such as Interleukin-1 and Tumor Necrosis Factor-Alpha that can alter sleep regulatory processes (Krueger & Karnovsky, 1995).

According to Spielman, Nunes, and Glovinsky (1996), the etiology of sleep disturbance in cancer patients can be divided into three main categories. The first consists of predisposing factors, traits that increase the individual's general vulnerability to developing sleep problems such as gender, age, genetics, presence of a psychiatric disorder, and personal history of insomnia. The second category is the precipitating factors, meaning situational conditions that trigger the onset of sleep problems including type of medical treatment, pain, delirium, and hospitalization.

The third consists of perpetuating factors, those that contribute to the maintenance of insomnia over time, such as maladaptive sleep behaviors and faulty beliefs and attitudes about sleep. The following descriptions are possible etiological factors related to sleep disturbance in cancer patients that have integrated Spielman et al's (1996) predisposing factors (e.g., age, gender, and functional status) and precipitating factors (e.g., environment, fatigue, pain, depression, cancer type and treatment)

Predisposing Factors of Sleep Disturbance

Age: Advanced age has been associated with changes in sleep patterns (Ancoli-Israel et al., 2000). When compared with the young, the elderly have longer sleep latency, more frequent night time awakenings, prolonged time awake after sleep onset (Gerard, Collins, Dore, & Exton-Smith, 1978; Hayter, 1983), earlier rising, more frequent daytime napping (Alapin, Fichten, Libman, Creti, Bailes, & Wright, 2000; Hayter, 1983; Webb, & Campbell, 1980) less deep sleep and more light sleep (Bliwise, 1997). The elderly commonly complain about light sleep. Sleep disturbance in the elderly is also associated with up to two times higher mortality rates when compared to a healthy elderly population without sleep problems (Wingard & Berkman, 1983). Bliwise (1997) reported that chronic illness has a greater influence on sleep patterns of the aged population than aging alone. More than 50% of people over 60 have experienced difficulty initiating or maintaining sleep (Alapin et al., 2000; Mellinger, Balter, & Uhlenhuth, 1985). Poor sleep is reported by 20% of people between the ages of 68 and 80. However, among cancer patients, older people reported less insomnia, less anxiety, depression and better quality of life than younger cancer patients, who experienced more insomnia regardless of gender (Redeker, Rev, & Ruggiero, 2000).

Gender: There are several differences in sleep characteristics between men and women. Women report more difficulties in initiating and maintaining sleep than men whereas men describe more sleep disturbances and among men the incidence of sleep difficulty increases with age (Bliwise, 1997; Polo-Kantola, 2001). Women have a greater tendency to react more to sleep disturbing factors than men. Also, women have longer wake times after awakening during the night, longer sleep latency, and thus lower sleep efficiency than men (Lindberg et al., 1997). Pregnancy, hormonal changes, and thermoregulation instability, specifically hot flashes, contribute to sleep disturbances. Hot flashes are an especially common symptom for prostate or breast cancer patients having hormonal treatment and with certain chemotherapy agents (i.e., tamoxifen). These hot flashes were statistically significantly related to poorer sleep quality in younger women due to premature menopause (Knobf, 1998; Mourits et al., 2002; Polo-Kantola, 2001; Shaver & Zenk, 2000; Stein, Jacobsen, Hann, Greenberg, & Lyman, 2000). The cessation of ovarian function at menopause results in a marked decrease of endogenous estrogen and progesterone secretion (Couzi et al., 1995; Knobf, 1998). In addition to cessation of menstruation, a wide range of biological functions, including sleep, is affected. Other factors in women's lives such as roles of wife, mother, and worker inside and outside the home may affect sleep patterns during their cancer treatment (Berger & Farr, 1999). According to Dodd's et al. (2002) ongoing randomized trial, in a sample of 62 women with stage I and II breast cancer, more than 50% continued to work full or part-time, and 72% still did most of the housekeeping work while simultaneously undergoing cancer treatment.

Functional Status: Cancer patients who were receiving radiation therapy with a lower Karnofsky performance status score reported more sleep disturbances (Miaskowski & Lee 1999). In a sample of 987 lung cancer patients, multivariate analysis showed that functional impairment was the most important risk factor in the exacerbation of depression and sleep problems (Hopwood, 2000). The diminished functional status of cancer patients may increase fatigue and decrease sleep quality (Winningham, 1991). In two related studies, it has been found that regular and moderate physical activity improves sleep-wake cycles, and decreases fatigue in cancer patients (Berger & Farr, 1999; Winningham, 1991).

Precipitating Factors

Environment: Environmental factors such as light or noise may affect the sleep of healthy individuals (Floyd, 1999; Gabor, Cooper, & Hanly, 2001; Sheely, 1996; Shochat, Martin, Marler, & Ancoli-Israel, 2000; Wallace, Robins, Alvord, & Walker, 1999). In an urban environment, noise from transport, industry and neighbors are common. Exposure to transport noise disturbs sleep in the laboratory setting, but generally not in field studies, where habituation or adaptation occurs (Stansfeld, Haines, & Brown, 2000). A sample of 105 healthy female volunteers listened to the noise level recorded in a coronary care unit at night while their sleep was monitored. When compared to sleep in a quiet environment, the volunteers in the noisy environment experienced poorer sleep efficiency, more difficulty falling and staying asleep, and difficulty in progressing from one stage of sleep to the next (Topf, 1992; Topf & Davis, 1993).

Insufficient light exposure during the day has been implicated as a cause of sleep fragmentation in healthy individuals as well as in the elderly (Campbell et al., 1995; Richardson & Malin, 1996; Shochat, Martin, Marler, & Ancoli-Israel, 2000). Another descriptive, retrospective, case control study showed a relationship between nighttime light exposure (illumination) and cancer. In a sample of 1606, case (n=813) and control (n=793), researchers investigated whether exposure to light at night may increase the risk of breast cancer by suppressing the normal nocturnal production of melatonin by the pineal gland, which may increase the release of estrogen by the ovaries (Davis, Mirick, & Stevens, 2001). Subjects were questioned about their sleep habits and bedroom lighting environment. The researchers found that the breast cancer risk was increased among subjects who did not frequently sleep during the night (O.R. 1.14, 95%CI=1.01-1.28). Night shift work was also found to be associated with increased breast cancer risk (OR. 1.6, 95%CI=1.0-2.5). However, the variables used to define exposure to light at night may be biased because the questionnaire data were collected after the breast cancer diagnosis for the case group of patients. The study's reliability depends on the memory of patients or the completeness of their medical records. Thus, it is possible that a woman's recall of prior sleep habits could be affected by her recent disease experience. Another weakness of this study is that it is impossible to obtain a fully comparable control group since data were gathered retrospectively (Brink & Wood, 1998). Light exposure might be one factor attributed to increasing risk of breast cancer, but it is not possible to determine the causal relationship between these two variables

Symptoms: Advanced cancer patients are polysymptomatic and tend to have a minimum of four concurrently occurring symptoms during cancer treatments, which may trigger sleep disturbances (Longman, Branden, & Mishel, 1997; Nail et al, 1991).

According to Walsh, Donnelly, & Rybicki (2000), there are ten prevalent symptoms but these vary among patients depending on the patients' age, gender, and type of cancer and performance status. Content and thematic analysis of open-ended interviews with cancer patients revealed that sleep problems were related to the experience of other symptoms and the individual's perception of the cancer and its treatment (Engstrom et al., 1999).

Fatigue: Fatigue is one of the most common symptoms and is a major obstacle to the maintenance of normal daily activity and quality of life in cancer patients (Ancoli-Israel et al., 2001; Berger & Farr, 1999; Berger & Higginbotham, 2000; Broeckel, Jacobsen, Horton, Balducci, & Lyman, 1998; Jacobsen et al., 1999; Moore & Dimsdale, 2002; Moore et al., 2001; Okuyama et al., 2000; Portenoy & Itri, 1999; Richardson & Ream, 1996; Schwartz et al., 2000; Vogelzang et al., 1997; Winningham, 1991) and is often one of the key reasons for discontinuing cancer treatment (Ancoli-Israel et al., 2001). Blesch et al., (1991) found that the prevalence of fatigue among cancer patients was as high as 99%. Cancer patients attributed their fatigue to a combination of factors, but most frequently mentioned treatment, changes in sleep patterns and other cancer-related symptoms (Richardson & Ream, 1996).

Moore et al. (2001) reported that patients' overall level of fatigue was related to the amount of time spent awake at night (r=0.77) as well as to depressive symptoms (r=0.81). Smet, Visser, Willems-Groot, & Garssen (1998) also documented significant correlations between post treatment fatigue, physical distress, functional disability, quality of sleep, and psychological distress and depression in breast cancer patients undergoing radiation therapy. Richardson and Ream (1996) related severe fatigue among their study participants to poor sleep quality. These study findings are consistent with those of Jacobsen et al. (1999) and Moore & Dimsdale (2002).

Greenberg, Sawicka, Eisanthanl, & Rosset (1992) studied 15 women who were undergoing radiation therapy for breast cancer and reported that their average sleep ranged from 7.5 to 8.2 hours during the first seven weeks of treatment. However, there were no significant differences from week to week during the course of treatment. In contrast, Greenberg, Gray, & Mannix (1993) showed that 15 men with prostate cancer experienced the greatest alteration of sleep during the sixth week of radiation therapy, the last week of full volume radiation. In the seventh week, when radiation was coned down, patients still slept relatively fewer hours. In addition, they found a significant association between serum levels of interleukin-1 (IL-1), fatigue, and sleep. An elevated serum level of IL-1 was noted between weeks one and four, the same time when the relative fatigue rating increased. Hours of sleep and level of IL-1 during radiation treatment were significantly correlated in 30% of the sample such that the higher the level of IL-1, the fewer the hours of sleep. The correlation was stronger in treatment weeks two and seven than in other weeks.

Cancer related fatigue can occur any time during the illness trajectory and is associated with poorer performance and sleep disturbances (Jacobsen et al., 1999). Cancer patients experienced severe fatigue even before starting treatment (Jacobsen et al., 1999). Berger (1995, & 1998) found that patients who receive chemotherapy experienced severe fatigue 48-72 hours after their chemotherapy. In a sample of 61 women with breast cancer who had completed chemotherapy, the level of fatigue was associated with sleep difficulty; especially with sleep quality and sleeping during the daytime, but not with sleep efficiency or sleep latency (Broeckel et al., 1998). Approximately 30% of almost 2,000 breast cancer survivors reported more severe fatigue related to sleep disturbances even after treatment (Bower et al., 2000).

It is difficult to discern which symptom triggers which outcome. For instance, does poor sleep lead to inactivity and fatigue, or vice versa? Monga, Kerrigan, Thornby, & Monga (1999) studied 36 prostate cancer patients to examine the relationships between fatigue, depression, quality of life, and sleep disturbances. They found that their participants had higher scores for fatigue at the completion of radiation therapy but their scores for depression and self-reported sleep quality remained unchanged. According to Monga et al. (1999), fatigue may not be the result of sleep disturbances or depression. The results of this study contrast with previous studies that found positive relationships between sleep, fatigue, and depression in cancer patients (Redeker et al., 2000).

Berger & Farr (1999) conducted a descriptive prospective study with repeated measurements involving 72 women who received chemotherapy after surgery for stage I and II breast cancer. They used the Piper Fatigue Scale at the start and midpoint of each chemotherapy cycle. Circadian activity/rest indicators were obtained using wrist actigraph for 96 hours at the start of each treatment and for 72 hours at the midpoint of each chemotherapy cycle. Their study focused on the relationship between women's daytime energy levels and nighttime restlessness. They found that women who were less active and had increased night awakenings reported higher cancer-related fatigue. Disrupted sleep often occurs at the midpoint of treatment, which is generally by the end of the third cycle of chemotherapy. Although patients slept for longer periods, they experienced sleep problems and a higher level of fatigue. This conclusion supports the previous findings of Mormont, DePrins, & Levi (1995). A limitation acknowledged by the authors was the differing sample sizes over the course of treatment. Therefore, women who were wearing actigraphy for each treatment cycle may not be representative of the entire sample.

Another limitation was a lack of baseline data before initial treatment, such data would be helpful for comparison purposes. However, using actigraphy to repeatedly measure 24-hour circadian activity/rest patterns in each cycle was a strength of this study and showed changes in activity level and fatigue over the course of treatment.

Pain: Pain is the common symptom experienced by cancer patients. At least 70% of terminally ill dying cancer patients experience pain, which interferes with their quality of life (Hammes & Caines, 1994; Twycross, Harcourt, & Bergl, 1996). Approximately 50% of cancer patients still suffer from poorly controlled pain. Portenoy et al. (1994) suggested that 90% of ambulatory cancer patients experience pain. Cancer pain has a substantial negative effect on mood, resulting in anxiety, depressive feelings, and disturbed cognitive functions (Strang, 1998). Also, difficulty managing pain can lead to poor sleep (Ancoli-Israel et al., 2001). McMillan, Tittle, Hagan, &Laughlin (2000) found that pain interfered with all activities and hospitalized patients had the highest interference scores for waking and sleep. Cleeland (1989) suggested that cancer pain and anxiety contributes to loss of sleep, inability to cope, and increased difficulties with cancer treatment. Patients may experience more severe pain at night when less distraction enables more time for self-reflection or because pain has a circadian rhythm of increasing intensity at night (Glynn & Lloyd, 1976). Painful stimuli present during various sleep stages, and general acute pain, disrupt both stage 2 light sleep and deep sleep in cancer patients (Moore & Dimsdale, 2002).

Strang's (1990) study reported that 58% of 84 patients with cancer-related pain had sleep disturbances. Pain interfered, at least moderately, with general activity and work in about half of the patients. More than half reported moderate or greater pain that interfered with sleep, mood, and quality of life. Morin, Gibson, & Wade (1998) examined the characteristics of sleep in cancer patients using a sleep survey. They found that cancer patients had more difficulties initiating and maintaining sleep and greater pain intensity and unpleasantness than did good sleepers with chronic pain. Also cancer patients had frequent shifts of the stages of sleep, significant mood disturbances related to pain, and psychological distress (Morin et al., 1998).

When studying pain in cancer patients, it is important to note the characteristics of pain such as chronic versus transient, the amount of metastasis involved (e.g., bone metastasis), the site of the cancer, and the stage of cancer as therapy must be tailored to meet the patient's need. Because pain is a significant barrier to good sleep and rest, it is crucial to proactively intervene and administer analgesics for effective pain management (Parker, 1995). Using analgesics for controlling pain helped more patients get back to sleep than any other intervention.

Depression: One of the most commonly reported psychological problems in cancer patients is depression (Hopwood & Stephens, 2000; Kurtz, Kurtz, Stommel, Given & Given, 2001). The prevalence of depression in cancer patients may be as high as 77%, especially among patients with advanced cancer (Bukberg, Penman, & Halland, 1984). Cancer patients often suffer from unrecognized and untreated long-term depression even after they overcome the disease symptom manifestation of depression which includes sleep disturbances, loss of interest in life, anxiety and irritation, fatigue, loss of concentration, and suicidal ideation (Bottomley, 1998). In a sample of 159 gastrointestinal cancer patients, 35% had anxiety and depression at the time of their diagnosis and six months later. The level of depression did not change over the treatment period, and coping and self-management improved minimally or not at all (Nordin & Glimelieus, 1999).

The negative impact of depression includes shorter survival time after a cancer diagnosis (Colon, Callies, Popkin, & McGlave, 1991), decreased physical functioning, and increased comorbidity. Even though there are approximately 1,000 studies about depression in cancer patients, an understanding of the relationship between depression and sleep in patients with cancer is extremely limited. Some studies indicate that younger cancer patients experience more psychological distress, anxiety, depression, and problems with sleeping (Walsh et al., 2000). In contrast, D'Antonio et al. (1998) reported that neither age nor gender had any influence on the occurrence of depression. Obviously, this area needs to be studied for further clarification.

Cancer type and treatment: Cancer cells, like other cells, are heterogeneous with respect to cell division. Some cells proliferate exponentially, others die or become dormant (Wang, 2000). The cancer may become the progenitor of cell division, continually creating more cells resulting in increased tumor mass (Haskell & Berek, 2001). Generally, cancer cells express abnormal antigens on their cell surface that activates immune cells, the immune cells recognize particular antigens on the cell surface and then work to kill the tumor cells. Immune cells are divided into two categories, one is the natural, consisting of nonspecific macrophages and natural killer cells and the other is acquired, consisting of specific T and B lymphocytes (Banasik, 1994). Individuals with cancer may have reduced populations of T and B-cells and may respond poorly to injected antigens (Krueger et al., 1998). Many immune factors such as interleukin-1, alpha-2, beta-endorphin and tumor necrosis factor have been shown to promote slow wave sleep. These cytokines, which are involved in immune regulation, are diminished by lack of sleep (Krueger & Karnovsky, 1995). Interleukin-1 levels increase during sleep and peak levels occur at the onset of slow wave sleep. Sleep deprivation leads to a variety of changes in immune function, including reduced antibody response to red blood cells, decreased lymphocyte DNA synthesis, and an increased number of circulating monocytes, granulocytes, and natural killer cells (Krueger et al., 1998).

Cancer patients may also exhibit either normal or markedly altered circadian rhythms (Mormont & Levi, 1997). According to findings from animal and human studies, these circadian rhythm alterations seem to depend on tumor type, growth rate, and level of differentiation. Cancer cells produce growth factors and hormones, which can change the central circadian system in the body. The progression of cancer and treatment modality may alter circadian rhythms by dampening the amplitude or shortening the rhythm to less than 24 hours (Mormont & Levi, 1997). Disruption in individual sleep patterns can disrupt circadian rhythms (Taub & Berger, 1976). Disruption of circadian rhythm can also result in changes in mood, functional status, and fatigue (Berger & Farr, 1999).

In addition to the sleep disturbance caused by cancer, chemotherapy agents, especially antimetabolites targeted to DNA synthesis such as cytarabine, floxuribine, fluorouracil, mercaptopurine, thioguanine and methotrexate are often used in the treatment of cancer and may cause insomnia as well (Berlin, 1984). Although this connection is not yet well established, there is statistically significant evidence to support a correlation. While patients are receiving chemotherapy, they often experience frequent nighttime awakening, insomnia, and an increased need to sleep and nap during the daytime, in addition to many other side effects (Knobf, 1998; Nail et al., 1991; Piper, 1993). Furthermore, during chemotherapy, patients may take steroids, such as prednisone, which increase appetite as well as sleeplessness (Asplund, 1999).

It is estimated that more than half of cancer patients will require radiation therapy during their illness (Wang, 2000). Radiation therapy, even though it is localized, often causes systemic side effects such as nausea, anorexia, and fatigue. These systemic side effects may, theoretically, promote the release of toxic waste products from tumor eradication into the blood stream, which in turn may cause sleep disturbance. The presence of these toxins may also account for gastric discomfort whereas this increase in metabolic waste products may be partially responsible for the frequent complaint of fatigue (Wang, 2000). The degree to which these systemic side effects manifest themselves varies from mild to severe depending on the tumor burden, the volume of the irradiation area, the anatomic site and the dose of radiation (Wang, 2000).

Correlates of Sleep Disturbances in Family Caregivers

From the time of a cancer diagnosis until the disease is cured or well controlled or when death results, each family member experiences a unique emotional reaction (Carter, 2002; Duhamel & Dupuis, 2004). The intensity of the caring for patient with cancer is magnified for the family caregiver who provides direct patient care at home. Caregiving is a complex activity affected by many influences and variables (Young & Kahana, 1989). Caregiving is associated with chronic stress and a decline in health (Schulz, Visintainer, & Williamson, 1990). This stressful situation can lead to negative outcomes, such as sleep disturbance, depression, fatigue and lower quality of life in the family caregiver. For instance, if sleep problems are prolonged for more than two weeks, it may result in negative emotional and physical outcomes such as changing glucose regulation, stress response, decrease immune function and increased mood disorders (Kiley, 1999;Scheen, & VanCauter, 1998; Zammit, Weiner, Damato, Sillup, & McMillan, 1999).

The etiology of sleep disturbance in caregivers has not been explicitly described, but there are several etiologic factors described in patients (e.g. age, gender, and environment) that are similar for caregivers. Some factors can directly impact sleep disturbance in caregivers while others such as quality of life can be influenced by the sleep disturbance. According to Spielman et al. (2001), the etiology of sleep disturbances in cancer patients is divided into three main categories. Taking Spielman et al. (1996) descriptions into consideration, the etiology of sleep disturbance in cancer caregivers can also be divided into three categories. The first consists of predisposing factors that may include gender, age, presence of a psychiatric disorder, personal history of insomnia, demographic component and role in the family. The second category consists of precipitating factors that may include caregiver's health status, financial status, immunity, caregiver burden. The third consists of perpetuating factors, which are maladaptive sleep behaviors and faulty beliefs and attitudes about sleep. The following descriptions are possible etiological factors related to sleep disturbance in cancer caregivers that have integrated Spielman et al. (1996) predisposing factors and precipitating factors.

Predisposing Factors of Sleep Disturbance

Caregiver Roles and Gender: Who takes on the role of caregiver as well as the gender of the caregiver may have an effect on how severe the consequences of caregiving are for the caregiver (Young & Kahana, 1989). Young and Kahana (1989) hypothesized that spouses suffer less distress than children as a caregiver, and males suffer less than females. Also, daughters suffer more burden and mental distress than wives or husbands. A total of 183 patient and caregiver dyads were interviewed six weeks after discharge from hospitalization for myocardial infarction. Mean age of caregiver was 60 years old, female and spouse of the patient. It was found that spouses performed mostly food preparation and housekeeping tasks while children associated more with personal care. Children reported a greater burden. Women tended to provide more care than men, offered a larger time commitment, and suffered greater physical and mental health consequences.

Precipitating Factors of Sleep Disturbance

Immunity: Taking care of an ill family member increases the level of stress and decreases immune function in the caregiver. The caring role affects immune systems and leaves them vulnerable to a variety of diseases (Fischman, 2003). One of the studies (Kiecolt-Glaser et al., 2003) compared men and women caring for a spouse with Alzheimer's disease to a similar group without caregiving responsibilities. Plasma samples from all participants were analyzed from six consecutive years. Caregivers of spouses who died during the study remained in the study so the researcher could collect data on their functioning once caregiving ended. The caregiving group (n=119) had a marked increase in Interleukin-6 (IL-6) over the course of six years, which was four times higher than for noncaregivers (n=106). A higher level of IL-6 was likely to be related to sleep disturbance, heart disease, and arthritis in the caregiving group. In addition, there were no statistically significant differences between former caregivers, those who had lost a spouse during the study, and current caregivers. This high level of the IL-6 did not change much over the course of the study.

Health Status: Caregiving produced damaging effects on the physical and mental health of approximately 15% of the overall caregiving population (Berg-Weger, Rubio, & Tebb, 2000). A number of researchers found that caregiving is linked to increased physical health problems (Baumgarten et al., 1992; Berg-Weger et al., 2000; National Family Caregivers Association (NFCA), 1997; Smerglia & Deimling, 1997). Kim & Lee (2003) found that one item in the caregiver's assessment of their current health status was highly correlated with the total score in a multilevel assessment inventory of physical health. Approximately 30% of caregivers rated their health status as poor due to caring for their ill family member.

Symptoms: Fatigue is one of the symptoms that can be experienced by caregivers. Persistent fatigue interferes with quality of life and functional capacity which limits one's ability to meet role expectations (Teel & Press, 1999). When role expectations include caregiving responsibilities, the presence of caregiver fatigue can have serious implications for both the caregiver and recipient (Teel & Press, 1999). Sato, Kanda, Anan, and Watanuki (2002) examined the sleep EEG and fatigue levels of nine female family caregivers (mean age = 65 years) and nine female noncaregivers (mean age=67 years) for two consecutive nights in their homes. They also used the Sleep Evaluation Questionnaire, EEG, Perceived Symptoms of Fatigue, and critical flicker fusion (CFF) frequency. The caregivers had a significantly higher percentage of Stage 1 (light sleep) and a lower percentage of Stage 2 (light sleep) during the 2nd cycle and a higher percentage of Stages 3 and 4 during the 3rd cycle of sleep than those of the noncaregivers. The caregivers reported a lower quality of sleep, a greater perception of experiencing fatigue symptoms, and a higher level of physical fatigue than noncaregivers.

Depression: Depressed mood can have a devastating effect on the caregiver's health and their ability to continue to provide care for their family member with cancer (Carter, 2002; Given, Given, & Azzouz, 1999). Family caregivers' depression scores were higher than noncaregivers' scores (Dura, Stuckenberg, & Kiecolt-Glaser, 1991; Russo, Vitaliano, Brewer, Katon, & Becker, 1995; Strawbridge, Wallhagen, Shema, & Kaplan, 1997; Tennstedt, Cafferat & Suyllivan, 1992). Several factors may be related to the caregiver's depression such as social support, patient's age, patient's cancer stage and functional status (Given et al., 1999; Kurtz, Given, Kurtz, & Given, 1994). The prevalence of caregiver's depression has been reported to be from 38% (Baumgarten et al., 1992) to 60% (NFCA, 1997). The level of depression appears to be transient and changes over time (Berg-Weger et al., 2000), which supports the "wear and tear" theory of caregiving that suggests caregivers' mental states may deteriorate through the course of caregiving (Berg-Weger et al., 2000; Schulz et al., 1993). There are several factors influencing the level of depression, such as poorer caregiver health, fewer financial resources, young age (Schulz et al.,1988), and also the number of stressors or level of distress experienced by the caregivers (Rankin, Haur, & Keefover, 1992). However, study findings are inconsistent. For example, Meshefedjian et al. (1998) report that spouse caregivers experienced higher levels of depression while other studies report less depression in spouse caregivers (Carter, 2002; Li, Seltzer, & Greenberg, 1999). Female caregivers experienced higher depression than males (Berg-Weger et al., 2000; Schulz et al., 1990) which is a different from Carter's report of an average Center for Epidemiological of Studies-Depression (CESD) score for males of 21.11 (SD 11.26) and females of 18.79 (SD 11.12)

Culture: Another aspect of sleep disturbance might be the influence of cultural background. Cultural background could influence how a person expressed their symptoms and which symptoms they chose to report (Wenger, 1993). Cultural norms and sociopolitical contexts directly and indirectly influence family caring (Connell & Gibson, 1997), and caregivers with different backgrounds are likely to perceive and react to caregiving in different ways (Kim & Lee, 2003). Lee & Sung (1998) compared the caregiver burden of Koreans and Whites in caring for elderly dementia patients. Korean caregivers had lower global burden, but after controlling for filial piety and extended family support, the two groups' differences were no longer statistically significant. Filial obligation and extended family support have been identified as important factors in predicting the burden for Korean caregivers.

Another study also showed the cultural aspects of caregiving. Youn et al. (1999) compared Korean, Korean American, and White on perceived burden of caring for the elderly with dementia. Familism can be defined by strong in-group feelings, emphasis on family goals, common property, mutual support, and the desire to pursue the perpetuation of the family which was measured by a 16-item scale measuring ideal-typical familism. Familism was highest in the Korean caregivers and lowest in the Whites, with Korean Americans in the middle. The Korean and Korean American caregivers had higher depression and anxiety than the White group.

In contrast to these two studies, Choi's (1993) study examined the predictors of caregiver burden using 169 primary caregivers of non-institutionalized impaired Korean elderly subjects. The findings of this study suggested that various non-cultural factors, including family income (Beta=-0.61, $p<0.001$) and caregiver's health status (Beta=0.20, $p<0.01$) were the stronger predictors for caregiver burden than the cultural factors (i.e., caregivers' congruency with the traditional norms and their acceptance of the norms).

Kim & Lee (2003) conducted a cross sectional descriptive study in a sample of 120 daughters and daughters-in-law in Korea who were caring for cognitively or functionally impaired elderly parents. This study examined the influence of cultural factors (roles, types of relationship, quality of intergenerational relationship and social network) and non cultural factors (age, income, health status, care recipient level of cognitive and functional impairment) as predictors of depression and physical health outcomes. The mean depression score, measured by CES-D-Korean, for the caregivers was 21.8 (SD=9.3), with a range of 14-49; 68% (n=81) scored above 16. Multiple regressions revealed that cognitive and functional impairment in care recipients, lower family income, caregivers' age (i.e. non cultural factors), were significant predictors, accounting for 32% of variance in health status. These findings are similar to those of Choi (1993). However, the findings from these studies are not directly generalizable to the cancer caregiver populations because in both the U.S. and Korea, the primary caregiver in the majority of cases is the spouse.

Literature Review of Sleep Disturbance in Oncology Patients

The literature review was conducted by using key words "cancer" "sleep" "pain" "fatigue" and "symptom" in Pubmed from 1966 to 2003. The literature review was organized chronologically. The research on sleep disturbances in the cancer population is extremely limited (Owen et al., 1999; Silberfarb et al., 1993; Yellen & Dyonzak, 1996). Of the more than 4,000 clinical trials on sleep, only 100 studies relate to sleep and cancer. Beginning in the 1980s, there was recognition of sleep disturbances in cancer patients, however, in most studies sleep disturbances was a secondary or an additional finding from the main study variables. From the review of these studies, ten studies were chosen because the major variables were focused on sleep, not on drug studies or phase I, II, III clinical trials. These ten studies stated that their main purpose was to describe sleep disturbances in cancer patients.

Kaye et al. (1983) compared the sleep patterns of cancer patients (n=30) to those of cardiac patients (n=22) and a healthy control group (n=24) with a 38-item questionnaire. They reported that cancer patients had more difficulty staying asleep than both the cardiac patients and the control group. However, cancer patients had no more difficulty falling asleep than the control group. Cancer patients had a sleep disturbance an average of 1.6 days a week and 16% mentioned pain as the cause of their sleep problem. Compared to other groups, cancer patients were much more likely to take sleeping pills or pain medication as an aid to sleep. This study's results contrast with those of Beszharczey and Lipowski (1977), who reported that cancer patients had more difficulty falling asleep and more difficulty staying asleep than hospitalized medical-surgical patients, when assessed by an 18-item questionnaire. Insomnia had a statistically significant association with depression and anxiety but not with pain.

Silberfarb et al. (1993) studied breast (n=17) and lung (n=15) cancer patients' sleep architecture and psychological state. Each cancer patient was matched to a healthy individual based on sex and age. The cancer patient's sleep was measured by polysomnography in a clinic and by sleep logs for two weeks. The study included 32 normal sleeping volunteers and 32 insomniacs. Lung cancer patients stayed in bed significantly longer, but obtained about the same amount of sleep as the breast cancer patients and the normal sleepers. The lung cancer patient's sleep efficiency (80%) was statistically significantly ($p<0.001$) poorer than the others (breast cancer patients 84.8%; normal 90.4%). Lung cancer patients had significantly ($p<0.001$) more difficulty falling asleep (63 minutes) than either the breast cancer patients (37 minutes) or the normal sleepers (26 minutes). Each night, the cancer patients were asked to indicate on a 100mm visual analog scale their level of difficulty sleeping, depression, anxiety, fatigue, and nausea. Breast cancer patients reported that they had more pain than lung cancer patients, and that it was sufficient enough to disturb their sleep ($p<0.01$). Lung cancer patients generally reported being satisfied with their sleep, and did not indicate sleep difficulties on visual analog scales. There were no statistically significant differences in depression or anxiety scores between groups of cancer patients. The researchers concluded that lung cancer patients underestimated their sleep disturbances when researchers compared their subjective and objective data.

Miaskowski & Lee (1999) conducted a pilot study on the relationship between pain, fatigue, and sleep disturbances over a 48-hour period in outpatients receiving radiation therapy for bone metastasis. They used subjective self-reporting tools and objective (wrist actigraph) instruments to measure sleep. The sample included approximately 42% breast cancer patients and there were 12 men and 12 women who participated. Sleep onset latency was greater than 12 minutes in 45% of the participants. The mean number of awakenings during the night, measured by actigraphy was 17.4 (SD 9.5), although the self-reported mean was 2.8 (range from 0 to 10). Naps were reported by 82% of the sample, which was positively related to the amount of sleep during the previous night (r=0.59, p=0.01). The mean sleep efficiency was 70.7% (SD 22.4). Patients with lower Karnofsky Performance status scores reported more sleep disturbance (r=0.51, p=0.02). The higher the percentage of total radiation therapy received, the lower the patients' sleep efficiency (r= -0.60, p=0.01). The pain score did not significantly change over 48 hours, but fatigue was higher both evenings than in the mornings.

Engstrom et al. (1999) used two phases to investigate sleep alterations in any stage of breast and lung cancer. In the first phase, the authors used an 82-item questionnaire in a telephone survey to elicit information on 150 patients. During the second phase, investigators were interested in the patient's perception of sleep problems and how they responded to them. The participants in the second phase were not entirely from the same group and came from a pool of patients with sleep problems and were randomly selected during their clinic visits.

The participants in the second phase were 42 patients, from the first phase who had sleep problems and were selected nonrandomly during their clinic visits. Investigators used qualitative methods to interview these 42 patients. In phase one, more than half of the patients were not receiving treatment for their cancer at the time of the study and 74% had been diagnosed at least two years before the study. In this sample, 44% reported a sleep problem during the past month. Sleep problems before the diagnosis were predictive of sleep problems after diagnosis (χ =5.82, $p<0.02$). There were no significant relationships between sleep disturbances and daytime naps, pain, or nausea. In addition, no significant relationships were found between sleep disturbances and stage of disease or treatment modality. In phase two, approximately half of the patients had a mild degree of sleep disturbance. The most frequent types of sleep problems were awakenings during the night, which occurred in 90% of the patients, sleeping fewer hours than normal (85%), and trouble getting back to sleep (75%).

Owen et al. (1999) conducted a secondary analysis of data from a previous descriptive correlational study. They used the Pittsburgh Sleep Quality Index (PSQI) for the first day of hospitalization to reflect the patient's perception of sleep during the month prior to hospitalization. Subjects included 15 patients with various types of cancer. These patients' responses were then compared with those from 52 healthy individuals. Patients with cancer reported significantly poorer sleep quality, sleep duration, sleep efficiency, and increased use of sleep medication than the healthy group. The cancer patients had an average global sleep disturbance score of 6.7 (SD=1.33), and the healthy group scored 2.7 (SD=0.23). A score of five is the cutoff point for severe sleep disturbances on the PSQI; higher scores indicate more severe complaints and worse sleep quality. The researchers concluded that overall sleep quality in cancer patients was poorer than in the healthy group.

Carpenter & Andrykowski (1998) also used the PSQI and measured the sleep quality in four different groups of patients: Bone Marrow Transplantation (BMT), renal transplantation, breast cancer survivors, and benign breast problems. Scores on the PSQI in all groups ranged from 6 to 7.9 and mean scores were higher than five, which was the established cutoff indicating poor sleep quality. Renal transplantation patients (7.9) and breast cancer survivors (7.0) had higher scores for global PSQI than BMT or benign breast problem patients. This study supported the findings of the Owen et al. (1999) study.

Redeker et al. (2000) conducted a secondary analysis of an existing data set to examine the relationships between symptoms of insomnia, fatigue, anxiety, and depression in a sample of 263 cancer patients who were receiving chemotherapy. The Functional Assessment of Cancer Treatment was used to measure quality of life. To measure anxiety and depression, the Profile of Mood States instrument was used. Fatigue and insomnia were measured by the Symptom Distress Scale. Insomnia, fatigue, depression and anxiety were positively associated with one another ($r=0.29$ to 0.69, $p<0.001$) and negatively correlated with quality of life ($r = -.28$ to $r = -.63$, $p < .001$). The investigators noted that women had more anxiety, fatigue, and poorer quality of life than men. The major finding was that 47% of the variance in quality of life could be explained by depression and anxiety. Fatigue and insomnia made a much smaller contribution (4% of the variance) to quality of life even though it was also statistically significant.

Cohen-Zion et al. (2001) studied sleep and quality of life over time in a sample of six breast cancer patients. Sleep was measured by wrist actigraphy and PSQI, and CES-D was used to measure depression. The Functional Assessment of Cancer Therapy-Breast cancer was used to measure quality of life. The PSQI's global sleep quality score ranged from 5 to 11. Total sleep time ranged from 7 to 8hrs, wake after sleep onset (WASO) ranged from 26 to 102 minutes, and the number of awakenings during the night ranged from 4 to 18. The mean score for depression was 21 on a scale of 0-60 (range 14 to 29). They found it to be statistically significant that patients with depression experienced less total sleep time, more WASO, and lower quality of life. This study showed that poor sleep quality is associated with lower quality of life ($r= -.90$, $p<0.05$) and higher depression ($r=0.52$, $p<0.05$).

Savard et al. (2001) studied prevalence and risk factors of insomnia in a sample of 300 women with non-metastastic breast cancer. Sleep was measured by a 33-item insomnia-screening questionnaire (author developed) and insomnia interview. Patients who reported sleep difficulties were subsequently interviewed over the phone to further evaluate the severity, duration, and course of their insomnia. Authors used the International Classification of Sleep Disorders (American Sleep Disorders Association, 1997) and DSM-IV (American Psychiatric Association) to determine insomnia; i.e., difficulty initiating (takes 30 min or more to fall asleep) or maintaining sleep (30 min or more nocturnal awakenings) with lower sleep efficiency (85%), and the sleep problem occurs at least three nights per week and causes significant daytime impairment or distress. Overall, more than 50% of the sample reported current insomnia symptoms and approximately 20% met diagnostic criteria for an insomnia syndrome. Among patients who participated in this study, 154 had insomnia symptoms, 61% reported taking more than 30 minutes to initiate sleep, while 72% reported being awake for more than 30 minutes at least one night per week. Eighty-six percent of patients complained of problems with sleep maintenance and 73% reported awakening too early in the morning. Of the patients who had insomnia, 95% of the cases were chronic. Among patients who completed the interview, 33% reported that the onset of their sleep difficulties followed the cancer diagnosis. Factors associated with an increased risk for insomnia were sick leave (OR=14.1), unemployment (OR=3.8), widowhood (OR=4.7), lumpectomy (OR=5.2), chemotherapy (OR=4.3), and an early stage of cancer at diagnosis (OR=0.46).

Davidson et al.(2002) examined the prevalence and nature of sleep disturbance in 982 patients with various types of cancer (breast, GI, GU, Gyn, Lung, Skin). The mean age was 64.9 (SD 12.5), 62% were female and 38% were male. Cancer diagnosis had occurred within the previous two years. Researchers used a sleep survey (author developed, 42 items) and patients reported excessive fatigue (44%), leg restlessness (41%), insomnia (31%), excessive sleepiness (28%), and multiple awakenings (76%). Duration of sleep disturbance was over 6 months for 75%; for 48% of patients, insomnia occurred up to 6 months before the cancer diagnosis, 6 nonth and for 18 months post diagnosis. The contributing factors for insomnia were houghts, concerns, and pain/discomfort.

Berger et al. (2002) conducted a clinical trial to evaluate outcomes of an intervention designed to promote sleep and modify fatigue after adjuvant breast cancer chemotherapy in 21 female breast cancer patients. The mean age was 55.3 (range 43-66). Researchers used daily diary, PSQI, wrist actigraph, Piper Fatigue Scale (PFS) on 7, 30, 60 and 90 days after the last chemotherapy and one year after the first chemotherapy treatment. Fatigue was not significantly different over time, ranging 2.9-3.3 on PFS and 2.9-3.5 on the daily fatigue scale. Sleep and wake pattern remained stable over time. The mean WASO (wake after sleep onset) was longer than 30 minutes with a wide range among the women (60-80 minutes).

Critique of Sleep Research in Cancer Patients

Design: Most studies were cross-sectional and descriptive in design; this design is appropriate in new areas of investigation. Engstrom et al. (1999) used only qualitative methods with semi-structured, open-ended interviews and content analysis for data analysis. Berger et al.(2003) used repeated measures to describe sleep and fatigue in cancer patients during and after chemotherapy. Choosing a cross- sectional study design is simple and economic, but it has several disadvantages such as recall bias susceptibility, unequally distributed confounders, and an association of two or more variables rather than causal relationships. For understanding sleep, a longitudinal study design or repeated measures is strongly recommended in investigating cancer patients problems. Cancer patients have many confounders from diagnosis to the point of remission or recurrence of cancer, which may trigger sleep disturbances.

Sample: Except for the Redeker et al. (2000) study (N=263), the Savard et al. (2001) study (N=300), and Davidson et al. (2002) study (N=982) most studies had relatively small sample sizes, which means that their findings are limited in their generalizability. Most previous sleep studies have used a small sample size because the measurement technology, such as laboratory polysomnography is expensive and time consuming to manage. Most patients included in the samples had one of the more prevalent cancers (e.g., breast, lung, prostate, or colon) with only a small portion diagnosed with lymphoma or another type of cancer. Overall, more than 80% of the participants were Caucasian with at least a high school education. The mean ages of participants ranged from 49.5 to 68 years. Two studies (Miaskowski & Lee, 1999; Silberfarb et al., 1993) recruited patients who received radiation therapy. Five studies (Berger et al., 2003; Cohen-Zion et al., 2001; Owen et al., 1999; Redeker et al., 2000; Savard et al., 2001) recruited chemotherapy patients. One study (Kaye et al., 1983) did not mention the type of the treatment patients were receiving.

Measurement: There is increasing use of objective sleep measurements such as wrist actigraphy or polysomnography, in cancer populations; however, these measurement were only used in five studies (Berger & Farr, 1999; Berger et al., 2003; Cohen-Zion et al., 2001; Miaskowski & Lee, 1999; Silberfarb et al., 1993). The remainder of the studies used self-administered subjective measurement tools such as the Pittsburgh Sleep Quality Index (PSQI)(Carpenter & Andrykowski, 1998; Owen et al., 1999), General Sleep Disturbances Scale (GSDS)(Miaskowski & Lee, 1999), Verran-Snyder Halpern Sleep Scale (VHS) (Thomas, 1987), Sleep Diaries (Miaskowski & Lee, 1999), or simply a record of hours slept (Greenberg et al., 1992,1993; Savard et al., 2001). The reliability and validity of wrist actigraphy has been reported and established in other clinical populations such as major depression patients, and insomniacs (Jean-Louis, Kripke, & Ancoli-Israel, 2000; Sadeh, Hauri, Kripke, & Lavie, 1995).

PSQI has been also proven to be valid and reliable in many clinical settings with an overall adequate internal consistency of 0.83 Cronbach's alpha coefficient. GSDS has demonstrated internal consistency in several cancer studies with over 0.80 Cronbach alpha coefficients. VHS has been used mainly in healthy populations, and in only one study of hospitalized cancer patients, but never validated with objective sleep measures. The sleep diary is commonly used in sleep research to measure sleep quality and sleep hours, however three studies (Greenberg et al., 1992, 1993; Savard et al., 2001) did not use psychometrically tested instruments. These studies

developed their own instruments to measure sleep, which possibly threatens the internal validity of study findings and makes it difficult to compare findings across studies.

Total sleep time ranged from 390 to 416 minutes (6.5-6.9 hours). Sleep latency (duration of time from bedtime to the onset of sleep) ranged from 15.1 minutes (among lung cancer patients) to 30.2 minutes (among bone metastasis patients) as measured by wrist actigraphy. Sleep efficiency ranged from 70.7 % (in bone metastasis patients) to 84.8 % (in breast cancer patients). Subjective and objective measurements often produced different results. For example, wrist actigraphy recorded 17.7 awakenings during one night but the subjective measurement reported only 2.8 times (Miaskowski & Lee, 1999).

Sleep Characteristics: In terms of sleep characteristics, cancer patients reported difficulty staying asleep, difficulty falling asleep, and awakening frequently during the night, depending on their type of cancer. However, only three studies (Engstrom et al., 1999; Kaye et al., 1983; Silberfarb et al., 1993) specifically identified the characteristics of sleep patterns in cancer patients. Additional studies are needed to more precisely describe the etiology of sleep disturbances, patterns of sleep, and objectively monitor sleep to enable more valid assessment of sleep disturbances.

Covariates: Another issue with these studies is that they overlooked clinically important covariates such as side effects of treatment, predisposing, precipitating, and perpetuating factors (e.g., age, gender, socioeconomic, environment), which may contribute to sleep disturbances in cancer patients even before the diagnosis. In addition, small sample sizes and homogeneous sample characteristics (e.g., White, middle class, high education) limit the general applicability of the study's findings. In future research, these covariates must be accounted for when considering the study design.

Literature Review of Sleep Disturbance in Family Caregivers

In a Pubmed search with key words 'caregiver' and 'cancer', more than 800 articles appeared, but using 'cancer', 'caregiver' and 'sleep' as keywords, only 10 articles emerged. Most of the sleep studies on caregivers have been done on patients with Alzheimer's or Parkinson's disease. There are few studies actually studying cancer caregivers' sleep problems. In this section, only five articles will be reviewed because only these five actually used sleep measurements to estimate sleep. One qualitative study used chemotherapy patients and caregivers; however, the main focus of the article was self care activity patterns during chemotherapy (Schumacher, 1996), so it was excluded from this review.

Teel & Press (1999) conducted a descriptive correlational study to compare perceptions of fatigue among older adults caring for a spouse with Alzheimer's disease, Parkinson's disease, or cancer with a control group of older adults. Individuals who cared for spouses with Alzheimer's (n=30), Parkinson's (n=32) and cancer (n=33) versus individuals whose spouses did not require exceptional care (N=33) agreed to participate. Participants completed several instruments Demographic, Visual Analog Scale for Fatigue (18 items), Verran and Snyder-Halpern Sleep scale (15 items), Symptom Distress Scale (13 items), Profile of Mood state-short form (30 items), Older Americans Resources and Services, Problematic Behaviors Scale, and Cognitive Status Scale.

All caregiving groups reported similar levels of fatigue, energy, sleep, and self-reported health. Fatigue level was 3.32 (mild fatigue) while energy level was 5.45 (0-10, higher number indicating more energy). All caregiver groups reported more fatigue ($p<0.001$), less energy ($p<0.001$), and more difficulty with sleep ($p<0.01$) than the control group. There were no statistically significant differences among the caregiving groups on these fatigue and sleep variables even though there were significant differences in caregiving situations as to the spouse's functional ability, cognitive status, and problematic behaviors.

Flaskerud et al. (2000) attempted to compare and describe distressing emotions-specifically depressive mood, anxiety, and anger and sleep problems in three groups of caregivers: AIDS (n=36), Age Related Dementia (ARD, n=40), and cancer (n=41). The three groups' mean age was 45.6, 70.6, and 51.5 respectively. The sample characteristics were approximately 80% of ARD and cancer caregivers were White, while they were only 28% of the AIDS caregivers. Three measurements were used: CES-D, Symptom Checklist 90-Revised, and PSQI. CES-D scores above 16 were found in 46% of caregivers of AIDS, 50% of ARD, and 41% of cancer. Cancer and AIDS caregivers were similar in feeling sad, bothered, difficulty getting going; feeling that everything was an effort. ARD and cancer caregivers were similar in feeling more positive, but AIDS caregivers had a higher percentage of feeling lonely, depressed, and that life is a failure. The majority of all three groups of caregivers had sleep problems. Cancer caregivers had the least problem falling asleep, but both they and AIDS caregivers had more restless sleep than ARDS caregivers. Cancer caregivers had greatest percentage of trouble staying asleep. The correlation between depression and sleep was moderately positive (r=0.53, p<0.01). Depressive mood was not significantly related to ethnicity, marital status, religion, education, or age; it was significantly related to lower income, hours per day of caregiving, care recipient functional disability, and number of care receiver symptoms. Among cancer caregivers, depressive mood was significantly related to anxiety, anger, patient's pain, and years of caregiving. Sleep problems were significantly related to depressive mood, anger and anxiety. ARD caregivers experienced fewer distressing emotions than either AIDS or cancer caregivers.

Carter and Chang's (2000), cross sectional, correlational study was used to describe the relationship between caregivers' sleep and depression. Fifty-one caregivers who were taking care of various types of cancer patients were recruited. Sleep and depression were measured by Pittsburgh Sleep Quality Index (PSQI) and Center for Epidemiological Studies-Depression (CES-D). The mean age for caregivers was 53 (SD 14.25), more than 80% were female, 84% were White, 60% were the spouse, and mean hours of caregiving were 15 (SD 8.28) per day. The mean level of sleep problem was 11.25 (SD 4.37), which was severe with 95% of the caregivers reporting severe sleep problems. The lowest sub scores of PSQI was sleep medication, because it prevented them from being able to monitor the care of patients' needs during the night. The depression was also higher than the cutoff of 16 for the risk for clinical depression (mean, 18.59, SD 10.53). There was strong positive correlation between sleep problems and levels of depression ($r=0.67$, $p<0.001$). This study's results were consistent with findings of other studies (Kurtz et al., 1996; Li, Seltzer, & Greenberg, 1999; Raveis, Karus, & Siegel, 1998).

Carter (2002) employed qualitative and quantitative methods to explore caregiver descriptions of sleep and depression and description of connections between these two variables over time. A total of 47 caregivers caring for advanced cancer patients participated with a mean age of 54. Most were female (81%), Caucasian (82%), married to the cancer patient (61%), and had provided care for an average of 24 months. Either a phone survey or interview based on caregiver preference was used to collect data with PSQI and CES-D. Mean PSQI overall sleep quality was 11.4 (SD=4.4) which indicated poor sleep quality (PSQI sleep quality >5). The mean depression score was 19.3 (SD=11.1), with males having higher depression (21.11, SD=11.26) than female caregivers (18.79, SD=11.12) which is different from other studies (Cairney & Wade, 2002; Silverstein, 1999), however, the gender difference was not statistically significant in this small sample. Non-spouse caregivers experienced more depression (22.13, SD=11.58) than spouses (17.74, SD=10.67). The investigator noted that the CESD scores matched with narrative comments in the interviews.

Carter (2003) further described family caregiver sleep loss and depression over a 10-week period. A descriptive correlational study design was used. Ten family caregivers of patients with a diagnosis of advanced stage cancer were recruited from an outpatient cancer clinic. The PSQI and CESD were measured every week over 10 weeks, and actigraph and sleep log were used for three separate 72-hour periods over the 10 week study period (1st, 5, and 10th week). The sample characteristics were mean age 61 years, hours of caring 19.7 hrs, sleep hours 6.3 hrs. Individual caregiver global PSQI sleep score ranged from 5 to 15 over the ten weeks.. The Global scores indicated a moderate sleep problem. Sleep efficiency was 74% on actigraph data which was lower than the sleep log's sleep efficiency score (80%). Depression scores ranged from 8 to 16 over the 10 weeks and varied widely from week to week. In week 1 to 7, approximately 50% of the caregivers reported CES-D scores at or above 16, a level considered to indicate an increased risk for the development of clinical depression. Discrepancies were noted between actigraph and sleep onset latency, duration, and sleep efficiency scores. Sleep and depression plots show large fluctuations over the 10 weeks. More than one third of their sample (N=159) had notable anxiety and depression at the time of their diagnosis and six months later, however, there were no significant change. Similarly, depression changing over time was not found in another study of gastrointestinal cancer (Nordin & Glimelieus, 1999).

Critique of Sleep Research on Family Caregivers of Cancer Patients

Design: Most studies were cross-sectional and descriptive in design, which is appropriate when entering new areas of investigation. Carter (2003) used repeated measures over a 10 week period. In the aforementioned critique of sleep research with cancer patients, a cross-sectional study design is simple and economic, but it has several disadvantages such as recall bias susceptibility, unequally distributed confounders, and an association of two or more variables rather than causal relationships. Caregiving of cancer patients could change over time because of changes in patients' functional status, disease progress, and financial status. Hence, a longitudinal study design or repeated measures is strongly recommended for investigating caregivers' sleep problems.

Sample: Sample size of all five studies was relatively small (range 10-51). Overall, more than 80% of the participants were Caucasian with at least a high school education. The mean age of caregivers ranged from 51 to 70 years. All of studies used caregivers recruited from outpatient clinics. All of Carter's three studies used caregivers who were caring for patients with advanced stages of cancer and mean hours spent caregiving were approximately 16 hours a day over a 24-month period.

Measurement: The five studies used self-administered subjective measurement tools such as the Pittsburgh Sleep Quality Index (PSQI), Verran-Snyder Halpern Sleep Scale (VHS), and Sleep logs. Carter (2003) was the only study to use an actigraph to measure objective sleep in caregivers. Reliability and validity were acceptable as reported in those samples who completed these scales. which is acceptable.

Sleep Characteristics: In terms of sleep characteristics, there are inconsistent findings in the five reviewed studies. Flaskerud et al. (2000) reported cancer caregivers had the least problem falling asleep, and experienced restless sleep and had trouble staying asleep, while Carter (2002) found that caregivers had trouble both with falling asleep and staying asleep. Sleep efficiency, according to Carter (2003), was lower for the caregivers (74%) than for healthy sleepers. Total sleep hours was approximately six hours which is less than recommended by the National Sleep Foundation. Discrepancies were noted between actigraph and sleep quality, latency, duration, and efficiency scores. Caregivers overestimated sleep latency and sleep efficiency in sleep logs (Carter, 2003).

Covariates: Many factors are correlated with sleep disturbance and directly or indirectly influence the sleep disturbance of caregivers. These factors include such things as depression, fatigue, caregiver's health status, financial status, and burden. Most of the studies measured these factors, however, since the majority of all samples was white, middle class, and with a high education level, it may be hard to generalize the study findings to all populations of caregivers.

Family Caregiver Research in Korea

In contrast to American aspects of independence and individualism, Koreans conceptualize the self in relationship to the family and other social interactions with groups (Youn, Knight, Jeong & Benton, 1999). Family loyalties and values are very high, and family relations are the most important of all social relationships (Lee &

Sung, 1998). Family interests are more important than individual members' interests and Korean's value family life highly and rely heavily on both the immediate and extended family for support.

Koreans value and continue to practice Confucian rituals, especially filial piety and loyalty to country (Sawyer & Easton, 1992). Cultural norms and sociopolitical contexts directly and indirectly influence family caring (Connell & Gibson, 1997), and caregivers with different backgrounds are likely to perceive and react to caregiving in different ways (Kim & Lee, 2003). Some aspects of sleep disturbance might be influenced by this cultural background.

Chang (1998) reviewed a total of 62 published articles, 132 master theses and 20 doctoral dissertations on family nursing research in Korea between 1970-1997. She found that the most frequently used family concept in the titles of the articles was family support (59 papers), followed by family function and family burden. The most frequently used family assessment tool was the Family Environment Scale. Approximately 83% of papers used survey method to collect data.

There are no studies on family caregiver's sleep disturbance, but there are several articles discussing quality of life for family caregivers of elderly dementia and cancer patients. Hence, these articles are briefly reviewed.

Yang, Song, & Kim (1998) examined stress and adaptation for family caregivers of chemotherapy patients in Korea. A total of 125 caregivers participated, with a mean age of 41 years, and 66.44% were female. The relationship between patients and family caregivers was spouse (40.9%), parents (22.6%), and adult children (14.8%). The most stressful situation noted for the family caregiver was the patient's future, followed by financial stress.

Cho & Kim (1997) examined family support, hope, and quality of life for cancer patients both during hospitalization and at home. A total of 143 patients participated in this study (45 home care and 94 hospitalized). In the aspect of family support, there was no difference between hospitalized and home care patients. Hospitalized patients had a higher score for hope and quality of life than the home care cancer patients. The patient's quality of life was moderately correlated with family support (r=0.42, p=0.001). The family member who was the primary caregiver was the most important resource for the patient. Family support was the method of choice for facing progression of the disease for the cancer patient.

Lee (1997) conducted a qualitative study of the lived experience for family caregivers of gastric cancer patients. The ten female spouses of gastric cancer patients who had treatment at a hospital participated. Family caregivers were interviewed using open-ended and descriptive questions. The most commonly used term describing their experience was "Magmacgam (feeling of helplessness)" which is psychological distress caused by high distress due to a high level of uncertainty. They were uncertain about the health of the patient and the future for the family caregiver, primarily because the mean age of the patient (approximately 50 years) in this study meant that they were still the main source of financial and social support for the family.

Conclusions

Since every human being spends one third of their life sleeping, sleep disturbance has quite a strong impact on his/her personal quality of life. Although little research has been conducted on cancer patients and their caregivers, findings in the few available studies have shown that sleep disturbances are highly prevalent among cancer patients and family caregivers, but are generally overlooked by health care providers. As has been discussed, there are many factors related to a cancer patient's and family caregiver's sleep disturbance. The specific characteristics of sleep disturbance in cancer patients are poorly understood. There are many confounding factors associated with sleep disturbance, however it is important to first recognize sleep disturbance as a problem and then to conduct thorough investigations, and to develop and test appropriate management strategies to improve sleep and quality of life for cancer patients (Engstrom et al., 1999) and their caregivers.

Sleep problems serve as a good indicator of psychological distress among cancer patients (Bleiker, Pouwer, Van der Ploeg, Leer, & Ader, 2000) and family caregivers (Kim & Lee, 2003). In addition, the number of symptoms experienced by any one patient may serve as a quality of life indicator (Portenoy et al., 1994). In order to improve our understanding of sleep disturbance it is necessary to consider concurrent symptoms such as pain, fatigue and depression in the cancer population (Dodd, Miaskowski, & Paul, 2001). Advanced cancer patients have multiple symptoms and need comprehensive individualized care with detailed attention to symptom management (Walsh et al., 2000).

There is very little research on cancer-related sleep disturbances in patients and family caregivers. Sleep disturbance in Korean cancer patients and their caregivers has been understudied. All of the existing studies were done in the United States. It is not known whether Korean cancer patients or their caregivers experience the same difficulties as their counterparts in the U.S., hence, it is important to study sleep disturbance in this population.

Moreover, the trend toward outpatient treatment of cancer has expanded the role of the family in illness management (Given et al., 2001; Northhouse, 1988). This situation is unsettling and distressing, and adds further to the stress already present when the patient is diagnosed. In Korea, when one family member becomes ill the primary responsibility of caring for that member falls on other family members. This system provides good support for the patient, but the burden on the family members is aggravated (Yang et al., 1998). Therefore, it is necessary for research to describe Korean cancer patients and their family caregivers sleep disturbance and then to develop and test symptom management strategies to alleviate the symptoms.

CHAPTER III

METHODOLOGY

Introduction

This chapter focuses on the methodology used in this study of sleep disturbance in gastric cancer patients receiving chemotherapy and their caregivers. The research design is descriptive and cross-sectional. The target population was individuals with gastric cancer and their family caregivers, and the sample was at one clinical site in an acute ambulatory care setting in Seoul, Korea. Subjects who met the criteria were consecutively entered in the study. This chapter is organized in the following manner: first, the study aims will be restated; second, a description of the variables and key terms used in this study will be given; third, a description of the setting, sample and data collection procedures, and instruments will be provided; and finally, the statistical analysis plan will be reviewed.

Study Aims

The purpose of this study was to: (a) describe sleep quality in gastric cancer patients who are receiving chemotherapy, (b) describe sleep quality in their family caregivers', (c) describe the gender differences in sleep quality in patients and family caregivers, (d) describe the relationships between other symptoms and sleep quality in cancer patients and their caregivers, and (e) describe the important predictors of cancer patients and their family caregivers' quality of life.

Definitions of Key Terms

Family Caregiver: "family caregiver" is an adult family member, or another individual who is an informal provider of in-home and community care to a cancer patient.

Fatigue: A subjective feeling of tiredness that is influenced by circadian rhythm and can vary in unpleasantness, duration, and intensity (Piper, Lindsey, & Dodd, 1987, p.19)

Habitual Sleep Efficiency (SE): proportion of sleep in the period potentially filled by sleep, ratio of total sleep time to time in bed.

Health Status: Subjective perception of present health status assessed with 0 to 10 scale (0=poor health, 10=perfect health)

Quality of life: A personal statement of positivity or negativity of attributes that characterize one's life (Padilla, Grant, & Ferrell, 1992. p.13)

Sleep: a state marked by lessened consciousness, lessened movement of the skeletal muscles, and slowed-down metabolism.

Sleep Disturbance: the perception or complaint of inadequate or poor-quality sleep because of one or more of the following: difficulty falling asleep, waking up frequently during the night with difficulty returning to sleep, waking up too early in the morning, unrefreshing sleep.

Sleep Quality: subjective perception of inadequate or poor sleep as assessed with PSQI.

Sleep Onset Latency (SOL): time period measured from 'lights out' or bedtime, to the beginning of sleep.

Sleep Pattern (24 hour sleep-wake pattern): Sleep pattern is the change in amount and timing of sleep within a 24-hour period of time, including total sleep time, sleep onset latency, wake after sleep onset, and time and place of sleep episodes.

Total Sleep Time (TST): amount of actual sleep time in a sleep period; equal to total sleep period less movement and awaken time.

Research Design

This research project utilized a descriptive, cross-sectional design to describe sleep quality in gastric cancer patients and their family caregivers.

Setting

The study was conducted in the infusion center at a tertiary teaching university hospital in Seoul, Korea. There are two infusion centers in the hospital, patients were assigned depending on the length of chemotherapy treatment. Patients who received less than 6 hours of chemotherapy stayed on the 1st floor infusion room (6 beds and 20 chairs), while patients receiving more than 6 hours of treatment were assigned to the

12th floor infusion room (23 beds). According to the hospital's 2001 statistics, the outpatient infusion centers had 75 patients a day with various types of cancer (e.g., gastric, lung, breast, and liver). In 2003, the number of patients who received chemotherapy at outpatient clinics increased by more than 50%. The main reason for the dramatic increase was a change in the treatment system and protocol from inpatient to outpatient therapy. Unless patients had high co-morbidity or experienced side effects, most chemotherapy was carried out in an outpatient setting.

Sample

Patients and family caregivers while at the outpatient infusion centers were invited to participate in this study. Subjects were selected based on the following inclusion criteria.

Inclusion criteria

Patients who:

1. Are over 18 years of age
2. Able to read and write in Korean
3. Have been diagnosed with gastric cancer
4. Already received 1st cycle of chemotherapy
5. Have a Karnofsky performance score equal to or greater than 60 (rated by researcher)

6. Are mentally able to understand and to complete the written informed consent
7. Has a family caregiver at home who is required to participate in the study
8. Have no history of major depression or sleep disorders

Family Caregivers who:

1. Agree to participate and are capable of providing informed consent
2. Are equal to or greater than 18 years of age
3. Are able to read and write Korean
4. Do not have chronic sleep disorders or depression or other psychic disorders.

The rationale for selecting gastric cancer patients is that it is the most common type of cancer in Korea. The rationale for excluding from the sample those individuals who have had major depression or sleep disorders is due to the effect these conditions and their treatment have on sleep patterns and other symptoms such as fatigue and depression.

Sampling Method

The sampling method was a convenience sampling.

Sample Size Determination

A sample size of 100 in each group, patients and family caregivers, will have 80% power to detect an effect size of 0.40 using a paired t-test with a 0.05 two-sided significance level. A total of 103 gastric cancer patients and 103 family caregivers were recruited for this study.

Data Collection Period

The data collection period was from August to October 2003.

Instruments

The study will utilize a demographic profile form including symptom checklist (Appendix A-PATIENTS, APPENDIX B-FAMILY CAREGIVERS), Sleep diary (Appendix C), Pittsburgh Sleep Quality Index (PSQI, Appendix D), Lee Fatigue Scale (LFS, Appendix E), Brief Pain Inventory (BPI, Appendix F), Center for Epidemiological Studies-Depression-Korean (CES-D-K, Appendix G), and Quality of Life Scale-Cancer (QOL-CA, Appendix HI). These instruments have been psychometrically tested and evaluated for validity and reliability. Table 1 shows variables, measurement, and psychometric evaluation of each measurement. It took approximately 45 to 60 minutes to complete and was done with the researcher during the interview except for the Sleep Diary. The Sleep Diary was given to patients and caregivers to fill out for 3 days, and then returned to the researcher by mail.

Table 1: Measurement of Outcomes of Patients and Family Caregivers

Variable	Measurement	# of items	Score range	Other investigator salpha	Present study Patients	Present study Caregivers
Sleep disturbance	Sleep diary	19	Descriptive	0.69-0.87	0.81	0.85
	PSQI	19	0-21 *	0.83	0.68	0.76
Fatigue	LFS	18	0-180 *	0.91-0.96	0.89	0.90

Pain	BPI	9	0-110*	0.82-0.97	0.90	0.90
Depression	CES-D-K	20	0-60*	0.85-0.90	0.83	0.88
Quality of Life	QOL-CA	33	0-330**	0.88	0.82	0.80

* (negative scoring): Higher scores mean worse sleep quality, fatigue, depression, and pain

** (positive scoring): Higher scores mean better quality of life

Sleep Diary: Daily sleep diary has 12 questions related to sleep which includes a categorical scale that asks about feeling rested, dreaming, alertness, times of awakening, and sleep quality. An additional seven questions about fatigue every evening and morning for three days were asked also in the Sleep Diary, modified from the Lee Fatigue Scale. Haythornthwaite, Hegel, & Kerns (1991) examined the use of sleep diaries in a sample of 46 patients with chronic pain. The sleep diaries include the number of hours slept, length of sleep onset, frequency of awakenings during the night that resulted in trouble falling back to sleep, early morning awakenings, quality of sleep, lack of restfulness, and the previous night's sleep compared to usual sleep. They found that duration of pain complaint was related to delayed sleep onset and lower quality of sleep. In addition, pain severity was related to fewer hours slept and delayed sleep onset. The internal consistency reliability coefficient ranged between .69 and .87. Sleep diaries have been used in various populations such as the healthy (Shapiro & Goldstein, 1998), those suffering pain (Wilson et al., 1998), narcolepsy (Rogers et al., 1993), depression (Jean-Louis et al., 2000), insomnia (Brooks III et al., 1993) and cancer population (Berger & Higginbotham ,2000; Miaskowski & Lee 1999; Silberfarb et al., 1993; Savard, Simard, Blanchet, Ivers, & Morin, 2001). The internal consistency of of this study was 0.81 in gastric cancer patients and 0.85 for family caregivers in the present study

Pittsburgh Sleep Quality Index: PSQI is a self-administered questionnaire used to assess sleep quality during the previous month (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989). It contains 24 items with 19 self-rated questions and five questions to be answered by a bed partner or roommate. Each item is rated on a four-point scale (0-3). The reliability and validity have been determined to be adequate in a previous cancer study (Carpenter & Andrykowski, 1998). A PSQI pilot study (2002) was done by the researcher in various types of cancer patients who were receiving chemotherapy in Korea, with an internal consistency of 0.72, which is acceptable. Cronbach's alpha of internal consistency was 0.68 in gastric cancer patients and 0.76 for family caregivers in the present study.

Lee Fatigue Scale(LFS): LFS (Lee, Hicks, & Nino-Murcia, 1991) contains 18 items used to measure fatigue severity (13 items) and energy (5 items). The higher score (range 0-180) means more fatigue. LFS can be used in a numeric rating scale of 0 to 10 or a visual analog scale. In this study, the researcher used the numeric scale.

LFS has been used in many healthy and other clinical populations, but infrequently used in the cancer population. However, this scale may capture the cancer patients' type of fatigue (morning or evening fatigue) related to sleep. It is easy to complete and takes less five minutes. In this study, only 13 items were used because some terms such as fatigue or tired can share same meaning in Korean. Internal consistency using Cronbach's alpha for the present study was 0.89 for patients and 0.90 for family caregivers.

Brief Pain Inventory (BPI): BPI has nine items and is a self-administered instrument. Each item is rated on an 11-point scale (0-10). The higher number indicates greater pain. The reliability and validity were verified in previous cancer research (Cleeland, 1989; Cleeland & Ryan, 1994). The Cronbach's alpha for this scale was over 0.90 for both patients and family caregivers.

Center for Epidemiological Studies-Depression (CES-D): CES-D is a 20-item self-administered instrument. The 20 items survey mood, somatic complaints, interactions with others, and motor functioning. The response format is 4-point likert scales, with range 0-3, with anchor point in terms of days per week 'rarely or none of the time (less than one day)' to 'most or all the time (5-7days)'. The total scores range from 0-60, with a higher score indicating greater impairment. People with a final score of 16 or higher are typically identified as depressive cases. This generally represents someone who has reported at least six items to be frequently present over the course of the previous week, or most of the 20 items to be present for a shorter duration. In a sample of nonrandom varied groups of residents in the community (540 Korean adults and 164 psychiatric patients in the hospital), the cutoff score for clinical depression was a score of 21 in the Korean version of CES-D-K (Cho, Nam, & Suh, 1998). This higher cutoff score as compared to those in Western countries may be due to different ways of expressing affect, especially the suppression of positive affect, in cultures based on Confucian ethics. The CES-D Korean version was found to be a reliable and valid instrument to use with the general Korean population (Cho et al., 1998). In this study, Cronbach's alpha for the CES-D-K was 0.83 for patients and 0.88 for family caregivers.

Quality of Life-Cancer: Quality of life-CA contains 33 items used to measure the quality of life in cancer patients. Each item is rated on a numeric scale from 0 (not at all) to 10 (extremely positive). The total possible score ranges from 0 to 330. A higher score indicates a better quality of life. The reliability and validity have been established in previous studies (Choe, Padilla, Chae, & Kim, 2001; Padilla, 1992). In this study, Cronbach's alpha was 0.82 for patients and 0.80 for family caregivers.

Demographic profiles: The subject completed a demographic profile questionnaire. It includes age, gender, income, education, marital status, living conditions (noise, room temperature, light), Karnofsky performance scale, and current symptomatology (Symptom Checklist of side effects of chemotherapy). It was developed by Dr. Dodd for use in previous studies (RO1 CA48312). The Karnofsky is used to rate of the physical abilities of the both patient and family caregiver based on the definitions provided on a 0 to 100 scale, in increments of 10 (Karnofsky, 1977).

Data Collection Procedures

The UCSF Committee of Human Research and AMC human subjects committee reviewed and approved the proposal before research was initiated. Before collecting data, the researcher contacted two clinical nurse specialists (CNS) in the oncology department who were in charge of gastrointestinal cancer patients in both the outpatient and inpatient areas. On a daily basis, from Monday to Thursday, one CNS in the outpatient clinic provided a list of possible candidates for this study to the researcher. The researcher discussed with the CNS about the chemotherapy regimen, time of therapy, availability of family caregivers, and verified the type of cancer through hospital computer system. The researcher approached the patients who were eligible for this study, explained it and asked them to participate. In this clinic, more than 95% of the patients were accompanied by family caregivers when they received chemotherapy, so the researcher also asked the family caregivers to participate in the study at the same time.

Once they agreed to participate in the study, the researcher showed the questionnaire booklet and sleep diary to patients and family caregivers and explained to them how to fill them out. Then patients and family caregivers were asked whether they preferred to fill out the questionnaire by themselves or have it read to them by the researcher. Some patients had the intravenous line in their right hand or felt too tired to read the questionnaires, so they asked the researcher to read it for them. Most of the caregivers completed the questionnaires by themselves. The researcher waited beside the patients and caregivers until they completed the questionnaires. At the interview, the questionnaires were reviewed to check for completeness. For the sleep diary, the researcher explained to the patients and the family caregivers how to fill out the dairy for three consecutive days. Once they completed the 3-day diary, they were asked to return it to the researcher by mail.

Challenges of Data Collection

Translation: Since Korean was used exclusively throughout the research process, all materials were translated into Korean. Burns and Grove (1997) suggested translating from the original language to the target language then back translating from the target language to the original language, using translators not involved in original translation. To minimize the bias from the translation process, the translated questionnaires in Korean were back translated. Also, the researcher tried to use previously validated instruments already used in Korean for this study. For instance, CES-D has been translated in Korean and tested on a large Korean population and the researcher conducted a pilot study of PSQI in various types of cancer with chemotherapy patients in Korea.

Perception of participant research in Korea: Since Koreans are usually unwilling to participate in any type of survey or interview (unpublished dissertation, Im, 1997), it was difficult approaching patients and caregivers to ask them to join this study. The study site's oncologists personally shared their difficulties in recruiting the patients for their drug studies before the researcher began the study. However, it was tremendously helpful to have the Clinical Nurse Specialist involved in recruiting the patients. She recommended this study highly to the patients and family caregivers, and explained how there were few studies conducted with Korean cancer patients and their sleep disturbance. Additionally, to increase participation and the completion of 40 minutes of interview time, patients received a 10 dollar gift certificate for the supermarket in the hospital. There was another 10 dollar gift certificate for those who returned their sleep diary.

Reliability of answered questions: One of the frequently used expressions in Korean is average ("botongiyo") and so-so ("gjugraeyo"). These two words were not interchangeable, but are used ubiquitously when answering questions in casual conversation. In addition, culturally and historically, Korean people do not want to verbalize an extremely positive or negative view of any question. These cultural dynamics will be detailed later in the discussion chapter. The researcher experienced these phenomena in several previous surveys in both the US and Korea, so when the patients were approached for this study, all interviews were conducted with an understanding of these cultural and historical perspectives.

Data Analysis

Research Question

1) What is the sleep quality for patients and their family caregivers with gastric cancer and who are undergoing chemotherapy?

Descriptive statistics were used to describe demographic variables, sleep quality, depression, fatigue, pain, and quality of life. Statistics included frequency, percentage, mean, standard deviation. Also a repeated measure analysis of variance was used to compare the two groups (patients and family caregivers) the three days of fatigue levels and sleep quality in sleep diary data.

Research Question

2) What are the differences in sleep quality between cancer patients and family caregivers?

To determine the differences between groups, patients and family caregivers, matched paired t-test was used.

Research Question

3) Is there a gender difference self-reported in sleep quality in cancer patients or in family caregivers?

To determine the differences between each group's (patients or family caregivers) gender differences, independent sample t-test was used to measure group (male and female) differences in continuous predictor variables and outcome variables of sleep quality, fatigue severity, depressive symptom frequency and quality of life.

Research Question

4) What is the relationship between the symptoms of fatigue and depression and sleep quality in patients and family caregivers, as well as with demographic variables?

To measure the strength of the relationship between demographic variables (e.g., age, gender, education, perception of health status, financial burden) and symptoms, Pearson r correlations coefficients were determined for relationships between sleep quality, depression, fatigue, and quality of life. An alpha criterion of 0.05 was accepted as significant. If the demographic variable was a categorical variable, then Spearman rho correlation was used.

Research Question

5) What is the impact of patients' symptoms on patient's quality of life, and what is the impact of the caregivers' symptoms on family caregiver's quality of life?

Multiple regressions were used to determine how well symptoms were able to predict quality of life. Multiple regressions provided information about the model as a whole and the relative contribution of each of the variables that make up the model. This model also allowed testing of whether adding an additional variable such as age, gender, or health status contributed to the quality of life of the model, over and above those variables already included.

CHAPTER IV

RESULTS

Introduction

Results of the study are presented in this chapter and will be organized as follows. First, a general description of the sample will be provided including acceptance and refusal of the potential subjects to participate in the study. Handling of missing data and outliers is reviewed. Following this, the results will be discussed in relation to the aims of this study: Aim 1) Descriptive statistics of sample characteristics and study variables of patients and family caregivers are presented; Aims 2 & 3) Comparisons of both groups' sleep quality and gender differences are presented; Aim 4) Bivariate correlations of each of the study variables and demographic variables are presented; and Aim 5) Predictors of quality of life for patients and family caregivers are presented.

Response Rate

During the data collection period, a total of 123 gastric cancer patients and their family caregivers met the inclusion criteria, and were approached by a single researcher for an explanation of the study and if they were interested, then informed consent was obtained. Among the 20 (16%) subjects who chose not to participate, 19 said that "it is bothersome to answer the questions" or "too tired to answer during chemotherapy," and one subject was hospitalized due to complications during chemotherapy. The first person contacted by the researcher was the one given the option to refuse, and depending on the patient's treatment schedule, either the patient or caregiver was the one who decided. The final sample consisted of 103 patients and family caregiver dyad samples for this study.

All 103 dyads were asked to fill out a demographic questionnaire as well as other questionnaires. For the 3-day sleep diary, of the 103 dyads, eight (7%) refused to complete it. Therefore, a total of 95 dyads agreed to complete the sleep diary; however, 68 (73%) dyads actually returned their completed sleep diary.

Testing the Assumptions of the Statistical Model

Prior to doing the planned statistical analyses, analyses were performed to determine if any of the assumptions of the statistical techniques were violated. Outliers, normality, and linearity were assessed by inspecting residual scatterplots. In the normal probability plot, data should lie in a reasonably straight diagonal line from bottom left to top right, which suggests no major deviation from normality (Palland, 2001). In the scatterplot of the standardized residuals, data were roughly distributed rectangularly, with most of the scores concentrated in the center.

Independence of observations, where each observation or measurement must not be influenced by any other, is important. The patient and caregiver dyads were independent although a particular patient and family caregiver were considered and paired t-tests were used correlated.. Frequently, the researcher read the questions aloud to the patients for them to answer and the caregiver may or may not have been within hearing distance.

Possible multicollinearity occurs when there is intercorrelation among variables when correlations between independent variables is greater than 0.80 (Glantz and Slinker, 1990). An examination of the correlation matrix (Table 29) showed that most correlations between variables were found from -0.58 to 0.56. Collinearity diagnostics suggested that there was no occurrence of multicollinearity.

Demographic Characteristics

Demographic characteristics of patients and family caregivers are presented in Table 2. Patient subjects included 71 males and 32 females whose age ranged from 24 to 69 years with a mean age of 52 (SD 10.1). Of family caregiver subjects, 80 (78%) were female, 23 (22%) were male; and their age ranged from 21 to 73 years with a mean age of 48 years (SD 11.4). Overall, more than 60% of patients and caregivers had at least a high school education, approximately 50% of patients changed their employment status since the cancer diagnoses but only 11% of the caregivers had done so. In both groups, 30% of patients and caregivers were still working full or part time. In the patient group, 45% were unable to work due to their health status. More than 50% of patients and family caregivers experienced previous sleep problems when the patient was first diagnosed with cancer. The perception of present health status ranged from 0 (very bad) to 10 (very good), with mean score 5.53 for patients and 6.85 for family caregivers which was significant different with paired t-test (t(102)=4.22, p<0.05).

Characteristics of the 103 patients, including living arrangement (conditions), marital status, chemotherapy cycle, type of chemotherapy, and financial responsibility are shown in Table 3. Approximately 92% of patients were married, 89% had good functional status, 52% lived in an apartment, and 78% thought they lived in a quiet place. More than 60% of the patients were in the 2nd or 3rd cycle of chemotherapy, 86% had had surgery for their cancer before chemotherapy. The average score for their perception of their financial status was 3.08 (SD=0.98) on the five point likert scale (1 barely surviving to 5 very well off), which indicated they had enough money for their daily needs.

Table 2. Demographic Characteristics of the Sample at Study Entry

	Patients N=103		Family Caregivers N=103	
Characteristics	N=103	%	N=103	%
Age (years)Range	24-69		21-73	
$\overline{X}$	52.29(SD 10.07)		48.25 (SD 11.37)	
Gender				
Male	71	68.9	23	22
Female	32	31.1	80	78
Education				
Below High school	41	39.4	38	36.9
High school	25	24.3	38	36.9
College graduate or above	37	35.9	27	26.2
Employment				
Full-time	24	23.3	28	27.2
Part-time	8	7.8	8	7.8
Unemployed	1	1	2	1.9
Retired	5	4.9	3	2.9
Homemaker	19	18.4	58	56.3
Unable to work due to health	46	44.7	2	1.9
Student	0	0	2	1.9
Changing employment				
Yes	52	50.5	11	10.7
No	50	48.5	92	89.3
Previous Sleep Problem				
Yes	66	64.1	56	54.4
No	37	35.9	47	45.6
Health Status (range 0 very poor health to 10 perfect health)				
$\overline{X}$	5.53 (SD 2.43)		6.85 (SD 1.82)	
Functional Status (range 1 feel normal to 8 need to be hospitalized)				
$\overline{X}$	2.53 (SD 1.39)		1.62 (SD 0.68)	

Table 3. Selected Demographic Characteristics of Patient (N=103)

Variables	N= 103	%
Marital status		
Married	95	92.2
Not married, living together	1	1
Widowed	1	1
Divorced	2	1.9
Separated	1	1
Never married	3	2.9
Living Condition		
Apartment	53	52
House	49	48
Chemotherapy cycle		
2nd	32	31.1
3rd	32	31.1
4th	20	19.4
5th	13	12.6
6th	6	5.8
Chemotherapy Agents *		
MDP	48	46.6
DXP	45	43.7
5Fu	9	8.7
CPT11 (irinotecan)	1	1
Cancer Surgery		
Yes	89	86.4
No	14	13.6
Financial Status		
Barely surviving	4	3.9
Getting behind	27	26.2
Breaking even	31	30.1
Moderately well off	37	35.9
Very well off	4	3.9

*MDP=mitomycin, doxifluridine, cisplatin *DXP= taxotere, Cisplatin, xeloda

Table 4 depicts the caregiver's relationship to the patient, and their caregiving responsibility for patients and other family members. More than 84% of the caregivers were the spouses of the patients, and 10.7% of caregivers were either the daughter or daughter-in-law, 87% of caregivers were female. Their subjective assessment of their caregiving responsibility for the patient was 81.6 % (SD 22.8) while their caregiving responsibility for other family members was 89.3 % (SD =15.6), and as seen in Table 5 female caregivers' scores showed more responsibility for caring for patients and other family members than male caregivers.

Table 4. Relationship between Patients and Caregivers

	N=103	%
Relationship with Patients		
Wife	67	65
Husband	19	18.4
Daughter	10	9.7
Son	3	2.9
Parents	2	1.9
Daughter in Law	1	1
Other relative	1	1
Friend	0	0

Table 5. Selected Demographic Characteristics of Family Caregivers (N=103)

	N	Caregiving responsibility of patients (0-100%)	Caregiving responsibility of other family members (0-100%)
Male	23	80 (18.3)	85 (16.5)
Female	80	82 (23.9)	90 (15.3)
Total	103	81.5 (22.8)	89.3 (15.6)

Aim 1: Sleep Pattern

PSQI (Pittsburgh Sleep Quality Index) and Sleep Diary were used to measure sleep quality in both patient and caregiver groups. The PSQI global scores and Sleep Diary results were not affected by any particular chemotherapy cycle the patient was on.

1. Sleep Pattern and Characteristics in Patients

A. PSQI

The scores for the sample are summarized in Table 6. For each sleep component, the possible score ranges from 0-3. The desired range is 0 or 1. The seven component scores can be summed to produce a global sleep quality score. Global score of 5 or higher indicate moderate sleep problems in at least three component areas or severe sleep problems in at least two areas. Global PSQI score was 6.92 (SD 2.62) for patients. Females had higher mean scores than male patients in six components except habitual sleep efficiency. Regardless of gender, daytime dysfunction had the highest score and use of medication had the lowest. Only two patients used medication three or more times a week to help them sleep. During the previous month, the average time for falling asleep was 22.96 minutes (SD=19.98) and average hours of sleep was 6.74 hours (SD=1.45). Approximately 85% of patients had higher than cutoff score of 5, and 36% of patients had higher than 8.

Table 6. Pittsburgh Sleep Quality Index (PSQI) Global and Component Means (±SD) in Patients and Family Caregivers.

	Patients (n=103)			Family Caregivers (n=103)		
	Total	Male	Female	Total	Male	Female
	N=103	N= 71	N= 32	N=103	N= 23	N= 80
Global Scores	**6.92 (2.59)**	**6.74 (2.72)**	**7.31 (2.37)**	**5.81 (2.20)**	**5.86 (2.22)**	**5.80 (2.21)**
Component Scores (range 0-3)						
Sleep Quality	1.33 (0.69)	1.28 (0.74)	1.46 (0.56)	1.13 (0.70)	1.04 (0.63)	1.16 (0.58)
Sleep Latency	1.24 (0.86)	1.23 (0.88)	1.25 (0.80)	1.19 (0.70)	1.08 (0.84)	1.22 (0.65)
Sleep Duration	0.67 (0.99)	0.67 (0.99)	0.68 (0.99)	0.51 (0.81)	0.65 (0.88)	0.47 (0.79)
Habitual Sleep Efficiency	0.22 (0.64)	0.30 (0.74)	0.06 (0.24)	0.17 (0.47)	0.30 (0.70)	0.13 (0.38)
Sleep Disturbance	1.26 (0.46)	1.21 (0.44)	1.37 (0.49)	0.99 (0.45)	1 (0.52)	0.98 (0.43)
Use of Sleep Meds	0.19 (0.52)	0.11 (0.32)	0.34 (0.78)	0.04 (0.21)	0.08 (0.29)	0.03 (0.19)
Daytime Dysfunction	1.00 (0.86)	1.92 (0.70)	2.12 (0.75)	1.75 (0.70)	1.69 (0.70)	1.77 (0.71)

B. Sleep Diary

Tables 7 to 11 describe characteristics of the patients' 3-day sleep diaries. There was a statistically significant correlation between first day and second day for sleep quality (r=0.82, p<0.05) and second day with third day (r=0.94, p<0.01). The first day and the third day's correlation was 0.60 but not significant. The average reported sleep hours each night over the three days was approximately 7 hours for all patients. Thirty-five (53.8%) patients had a sleep latency of greater than 15 minutes on the first day, and this number was quite similar in patients for the following 2 days of sleep (60.3%, 54.2% respectively). The diaries indicated that more than 80% of patients woke up during the night, and approximately 60% were awake for more than 5 minutes. Naps were reported by approximately 60% of the patients in their 3-day diary.

Table 7. Patients' and Family Caregivers' Reporting of Taking Naps

		Day 1		Day 2		Day 3	
		Yes	No	Yes	No	Yes	No
		N(%)	N(%)	N(%)	N(%)	N(%)	N(%)
Patients	Male	33 (48.5%)	20 (29.4%)	29 (43.3%)	23 (34.3%)	35 (51.5%)	18 (26.5%)
	Female	10 (14.7%)	5 (7.4%)	9 (13.4%)	6 (9%)	7 (10.3%)	8 (11.8%)
	Total	**43** **(63.2%)**	**25** **(36.8%)**	**38** **(56.7%)**	**29** **(43.3%)**	**42** **(61.8%)**	**26** **(38.2%)**
Family Caregivers	Male	3 (4.4%)	9 (13.2%)	2 (2.9%)	10 (14.7%)	1 (1.5%)	11 (16.7%)
	Female	20 (29.4%)	36 (52.9%)	19 (27.9%)	37 (54.4%)	21 (31.8%)	33 (50%)
	Total	**23** **(33.8%)**	**45** **(66.2%)**	**21** **(30.9%)**	**47** **(69.1%)**	**22** **(33.3%)**	**44** **(66.7%)**

Table 8. Sleep Diary : Falling Asleep (sleep latency)

		Morning1		Morning 2		Morning 3	
		Mean	SD	Mean	SD	Mean	SD
Patients	Male	17.45	11.80	20.06	13.63	20.76	14.49
	Female	14.85	8.52	16.60	13.36	12.38	8.20
	Total	**16.89**	**11.16**	**19.23**	**13.54**	**18.91**	**13.75**
Family Caregivers	Male	10.08	6.94	14.00	15.32	8.50	3.34
	Female	17.76	15.10	18.94	14.57	15.14	10.45
	Total	**16.39**	**14.26**	**18.03**	**14.72**	**14.03**	**9.94**

Table 9. Sleep Diary: Did you wake during the night?

		Morning 1		Morning 2		Morning 3	
		Yes	No	Yes	No	Yes	No
Patients	Male	46 (67.6 %)	7 (10.3 %)	45 (66.2%)	8 (11.8%)	45 (67.2%)	7 (10.4%)
	Female	13 (19.1%)	2 (2.9%)	12 (17.6%)	3 (4.4%)	12 (17.9%)	3 (4.5%)
	Total	**59 (86.8%)**	**9 (13.2%)**	**57 (83.8%)**	**11 (16.2%)**	**57 (85.1%)**	**10 (14.9%)**
Family Care givers	Male	6 (8.8%)	6 (8.8%)	5 (7.4%)	7 (10.3%)	4 (5.9%)	8 (11.8%)
	Female	34 (50%)	22 (32.4%)	35 (51.5%)	21 (30.9%)	35 (51.5%)	21 (30.9%)
	Total	**40 (56.6%)**	**28 (41.2%)**	**40 (58.8%)**	**28 (41.2%)**	**39 (57.4%)**	**29 (42.6%)**

Table 10. Sleep Diary: Were any awakenings longer than 5 minutes?

		Morning1		Morning 2		Morning 3	
		Yes	No	Yes	No	Yes	No
Patients	Male	27 (47.4%)	18 (31.6%)	26 (45.6%)	19 (33.3%)	28 (48.3%)	18 (31%)
	Female	9 (15.8%)	3 (5.3%)	7 (12.3%)	5 (8.8%)	8 (13.8%)	4 (6.9%)
	Total	**36 (63.2%)**	**21 (36.8%)**	**33 (57.9%)**	**24 (42.1%)**	**36 (62.1%)**	**22 (37.9%)**
Family Caregivers	Male	3 (7.7%)	3 (7.7%)	1 (2.6%)	3 (7.7%)	1 (2.6%)	1 (2.6%)
	Female	20 (51.3%)	13 (33.3%)	15 (38.5%)	20 (51.3%)	23 (60.5%)	13 (34.2%)
	Total	**23 (59%)**	**16 (41%)**	**16 (41%)**	**23 (59%)**	**24 (63.2%)**	**14 (36.8%)**

Table 11. Sleep Diary: Total Sleep Hours Per Night (excluding naps)

		Sleep hours 1		Sleep hours 2		Sleep hours 3	
		Mean	SD	Mean	SD	Mean	SD
Patients	Male	6.61	1.43	6.99	1.37	7.00	1.66
	Female	6.86	1.90	6.71	2.30	7.08	1.65
	Total	**6.67**	**1.54**	**6.93**	**1.60**	**7.01**	**1.65**
Family Caregivers	Male	6.90	1.52	7.00	1.02	6.66	1.37
	Female	6.65	1.34	6.90	1.57	6.80	1.52
	Total	**6.69**	**1.37**	**6.92**	**1.49**	**6.78**	**1.49**

The average sleep quality of patients was rated as 2.6 (fair sleep) on a 5-point scale (with 1=very poor to 5=very good). The average alertness and sense of being rested for patients was 2.5 (somewhat drowsy) and 2.6 (somewhat rested) on a 4-point scale (with 1=very alert and 4=very drowsy, 1=very rested and 4=not at all rested). Daytime activity level was 2.3 (basic activity) on a 5-point scale (with 1=no activity and 5=strenuous activity). The summary is seen in Table 12 and Table 13.

Table 12. Sleep Diary: Morning Reports over 3 Days

		1st day			2nd day			3rd day		
		Alert (1-4)	Rested (1-4)	Sleep quality (1-5)	Alert (1-4)	Rested (1-4)	Sleep quality (1-5)	Alert (1-4)	Rested (1-4)	Sleep quality (1-5)
		Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Patients	Male	2.62 (0.71)	2.54 (0.77)	2.79 (0.71)	2.49 (0.60)	2.54 (0.57)	2.62 (0.56)	2.50 (0.60)	2.64 (0.62)	2.490 (0.65)
	Female	2.66 (0.61)	2.93 (0.79)	2.26 (0.70)	2.26 (0.70)	2.53 (0.91)	2.46 (0.63)	2.53 (0.63)	2.53 (0.74)	2.46 (0.63)
	Total	**2.63 (0.68)**	**2.63 (0.78)**	**2.67 (0.74)**	**2.44 (0.63)**	**2.54 (0.65)**	**2.58 (0.57)**	**2.51 (0.61)**	**2.61 (0.64)**	**2.48 (0.68)**
Family care givers	Male	2.50 (0.52)	2.50 (.67)	2.83 (0.38)	2.50 (0.52)	2.42 (.66)	2.83 (0.57)	2.50 (0.67)	2.42 (0.66)	2.67 (0.65)
	Female	2.70 (0.71)	2.62 (0.75)	2.75 (0.61)	2.59 (0.68)	2.61 (0.65)	2.77 (0.60)	2.59 (0.65)	2.50 (0.63)	2.68 (0.66)
	Total	**2.66 (0.68)**	**2.60 (0.73)**	**2.76 (0.57)**	**2.57 (0.65)**	**2.57 (0.65)**	**2.78 (0.59)**	**2.57 (0.65)**	**2.49 (0.63)**	**2.68 (0.65)**

*Alert (1 very alert-4 very drowsy), Rested (1 very rested- 4 not at all rested), Sleep quality (1 very poor-5 very good)

Table 13. Sleep Diary: Patients' and Family Caregivers' Activity Levels

			Activity Level		
			PM 1**	PM 2**	PM 3**
		N	Mean(SD)	Mean (SD)	Mean (SD)
Patients	Male	53	2.33 (0.87)	2.28 (1.00)	2.39 (0.92)
	Female	15	2.26 (0.96)	2.40 (1.12)	2.26 (0.96)
	Total	**68**	**2.32 (0.88)**	**2.30 (1.02)**	**2.36 (0.92)**
Family caregivers	Male	12	2.75 (1.05)	2.67 (0.88)	2.67 (0.98)
	Female	56	2.88 (1.13)	2.91 (0.96)	2.71 (0.92)
	Total	**68**	**2.85 (1.09)**	**2.87 (0.95)**	**2.71 (0.93)**

Reported in the Evening

Activity Level (1 no activity, 2 basic activity, 3 mild exercise, 4 moderate exercise, 5 strenuous exercise)

PM**1,2,3=first day, second day, and third day evening

2. Sleep Quality and Characteristics in Family Caregivers

A. PSQI

The scores for family caregivers are also summarized in Table 6. As seen in Table 6, global PSQI score was 5.8 (SD 2.20) for family caregivers. There were no differences between male and female caregivers on six components. Use of medication was the lowest for family caregivers while daytime dysfunction was the highest. There were no family caregivers using medication more than three or more times a week to help them sleep. Only five caregivers used medication for less than a week.

B. Sleep Diary

Tables 7 to 11 describe sleep variables in family caregivers. Complete data were available for 68 family caregivers. There were statistically significant moderate correlations between all three days (range $r=0.37-0.53$, $p<0.01$) in sleep hours, sleep quality, and AM and PM fatigue levels. In Sleep Diary studies, if the correlation is high enough ($r>0.60$) then a mean score for three days might be used. In this study, the correlation was moderate so the researcher examined a one-way repeated measure ANOVA to explore the changes over the three day period in sleep quality score, total sleep hours, and fatigue levels. There was no significant effect for time in either group on any day. A two-way repeated measure ANOVA was then used to explore the impact of time (days) and group (gender) on levels of sleep quality, total sleep hours, and fatigue level. There was no statistically significant main effect for time and group or also no time and group interaction effect.

The total sleep averaged score for caregivers across the three nights was 6.8±1.5 hrs. Thirty-two (47.8%) family caregivers took longer than 15 minutes to fall asleep the first night, then 51% and 44% on the next two nights. More than half of the caregivers woke during the night, which was consistent for all three consecutive days, and approximately 60% of their awakenings were for more than five minutes.

The average sleep quality of caregivers was rated as 2.75 (fair sleep) on the same 5-point scale. The average alertness and sense of being rested for caregivers was 2.56 (somewhat drowsy) and 2.52 (somewhat rested) on the earlier described 4-point scale. Naps were reported by 22 (32%) of the 68 family caregivers in their 3-day diary, and naps were significantly more frequent among women than men. Activity level during the daytime was 2.78 (mild activity) in family caregivers. The summary of sleep quality and activity level is presented in Table 12 and Table 13

Aim 2. Compare Both Groups' Sleep Quality

Group differences between Patients and Family Caregivers

A paired t-test was conducted to compare the global sleep score and seven components for patients and their caregivers. There were significant differences between global PSQI scores for patients ($\overline{X}$=6.92, SD=2.62) compared to their caregiver ($\overline{X}$=5.81, SD=2.20; t(102)=3.44, p=0.001), indicating that patients had more sleep disturbance than family caregivers. One interesting point was that the correlation between these two score was only 0.09. Matched paired t-test was also conducted to compare 7 components in both groups. There were three significant differences among the 7 components; sleep quality (t(102)= 2.45, $p<0.05$), sleep disturbance (t(102)=4.52, $p<0.001$), and daytime dysfunction (t(102)= 6.89, $p<0.005$). The patient group had slightly higher scores in six components, but the caregiver group had significantly more daytime dysfunction than the patients. In spite of these differences, the correlation between scores on all 7 components ranged from 0.04 to 0.19 which demonstrates little correlation between patient's and family caregiver's sleep quality. The summary of these scores is shown in Table 14.

Table 14. Paired Samples *t*-Test between Patients and Family Caregivers

	t	Sig.	Mean diff	SD	95% Confidence		Correlation
					Lower	Upper	
SLEEP QUALITY	2.45	.02	.20	.844	.02	.38	.15
SLEEP LATENCY	.56	.58	.05	1.05	-.16	.26	.09
SLEEP DURATION	1.36	.18	.17	1.16	-.08	.41	.19
HABITUAL SLEEP EFFICIENCY	.53	.59	.05	.74	-.10	.20	.14
SLEEP DISTURBANCE	4.51	<.001	.27	.63	.14	.38	.06
USE OF SLEEP MEDS	1.63	.11	.14	.54	.02	.25	-.06
DAYTIME DYSFUNCTION	-6.89	<.001	.23	1.10	.03	.43	.04
GLOBAL SCORE OF PSQI	3.44	<.001	1.11	3.26	.44	1.77	0.09

Aim 3. Gender Differences in Sleep Variables

A. Gender Differences

An independent sample t-test was conducted to compare sleep quality between men and women patients and men and women caregivers. For patients' group, there were no statistically significant differences in global sleep quality scores between males ($\overline{X}$=6.74, SD=2.72) and females ($\overline{X}$=7.31, SD=2.37; t (101)=1.01, p=0.31) and no difference in any of the seven component scores. The same was true for family caregivers; scores for males were similar ($\overline{X}$=5.86, SD=2.22), to females

($\overline{X}$=5.80, SD=2.21; t(101)=0.13, p=0.89). There were also no statistically significant differences in any component score by gender for family caregivers. The summary of these scores is shown in Table 15 and Table 16.

Table 15. Independent Samples *t*-Test: Gender Differences in Patients (N=103)

	t	Sig. (2-tailed)	Std. Error Difference	95% Confidence Interval of the Difference	
				Lower	Upper
SLEEP QUALITY	1.27	.20	.14	-.47	.10
SLEEP LATENCY	.058	.95	.18	-.37	.35
SLEEP DURATION	.054	.95	.21	-.43	.40
HABITUAL SLEEP EFFICIENCY	1.72	.08	.13	-.03	.50
SLEEP DISTURBANCE	1.67	.09	.09	-.35	.03
USE OF SLEEP MEDS	2.06	.06	.11	-.44	-.00
DAYTIME DYSFUNCTION	1.27	.20	.152	-.49	.10
GLOBAL SCORE OF PSQI	1.01	.31	.55	-1.67	.54

Table 16. Independent Samples *t*-test: Gender Differences in Sleep Quality (PSQI) Caregivers

	t	Sig. (2-tailed)	Std. Error Difference	95% Confidence Interval of the Difference	
SLEEP QUALITY	-.84	.40	.140	-.39	.16
SLEEP LATENCY	-.83	.40	.16	-.46	.19
SLEEP DURATION	.91	.36	.19	-.20	.55
HABITUAL SLEEP EFFICIENCY	1.49	.13	.11	-.05	.38
SLEEP DISTURBANCE	.11	.90	.10	-.20	.22
USE OF SLEEP MEDS	.96	.33	.05	-.05	.15
DAYTIME DYSFUNCTION	-.47	.63	.16	-.41	.25
GLOBAL SCORE OF PSQI	.13	.89	.52	-.96	1.10

B. Comparison of Both Groups' Morning and Evening Fatigue

Table 17 describes the morning and evening fatigue for both patients and family caregivers over 3 days. Patients and caregivers were asked to complete the modified short version (7-item) of the Lee Fatigue Scale prior to sleep (i.e., PM1, PM2, PM3) and upon awakening (i.e., AM1, AM2, AM3) for three consecutive days. On the first night (i.e., PM1), the average level of fatigue prior to sleep onset ranged from 1 to 7.83 on the modified Lee Fatigue Scale with a mean of 5.12 (SD 1.72). The patients' chemotherapy cycle had no effect on the fatigue score.

Table 17. Differences in Evening and Morning Fatigue as Reported by Patients and Family Caregivers.

		PM1 Mean (SD)	AM1 Mean (SD)	PM2 Mean (SD)	AM2 Mean (SD)	PM3 Mean (SD)	AM3 Mean (SD)
Patients	Male	5.06 (1.70)	4.89 (1.70)	4.86 (1.90)	5.11 (1.63)	5.31 (1.76)	5.11 *(1.77)*
	Female	5.33 (1.83)	5.55 (1.98)	5.86 (2.35)	5.16 (2.49)	5.25 (1.98)	4.94 *(1.73)*
	Total	**5.12 (1.72)**	**5.03 (1.77)**	**5.08 (2.03)**	**5.12 (1.83)**	**5.30 (1.79)**	**5.07 (1.75)**
Family Caregivers	Male	5.03 (1.99)	4.13 (1.65)	4.76 (2.16)	4.21 (1.93)	4.39 (1.79)	4.43 (1.88)
	Female	5.54 (1.63)	5.15 (1.61)	4.99 (1.75)	4.99 (1.90)	5.25 (1.59)	4.85 (1.76)
	Total	**5.45 (1.69)**	**4.97 (1.65)**	**4.95 (1.81)**	**4.85 (1.91)**	**5.10 (1.65)**	**4.78 (1.78)**

AM and PM—tired, sleepy, drowsy, worn out, concentration, desire to close my eyes, desire to lie down

Of the 68 patients who completed the first evening section of diary, 22 (32.4%) went to bed severely fatigued (>6) and 38 (55.9%) perceived themselves as moderately fatigued prior to bedtime. Only eight patients reported mild fatigue. Similar levels of fatigue were reported in the morning, as well, as demonstrated in the above table. The level of fatigue the first morning (i.e., AM1) ranged from 1.5 to 9.17 with the mean 5.03 (SD 1.77). Twenty-one (30.9%) woke up severely fatigued and 30 (44.1%) reported moderate fatigue, and 17 (25%) patients woke up with mild fatigue. This pattern was similar across all three days when they reported their morning

fatigue levels. In this study, however, there were no statistically significant changes in fatigue over time in either patient or family caregiver groups, and no statistically significant differences between morning and evening fatigue levels in either (Table 18 and Figure 2 and 3). Also the interaction effect (time and group) was not statistically significant. According to Lee (2001), the levels of morning fatigue can be improved by adequate rest or sleep on a diurnal basis (Lee, 2001). However, for these study participants, sleep did not seem to alleviate patients' or caregivers' morning fatigue.

Table 18. Repeated Measures Analysis of Variance for Morning and Evening Fatigue Differences

Tests of Within-Subjects Effects

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
TIME	5.846	2	2.92	1.52	.21
TIME * GROUP	1.80	2	.90	.47	.62
Error(TIME)	512.74	268	1.91		

Tests of Between-Subjects Effects

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Intercept	15.34	1	15.34	6.83	.01
GROUP	4.44	1	4.44	1.98	.16

Fig 3. Morning and Evening Fatigue in Patients

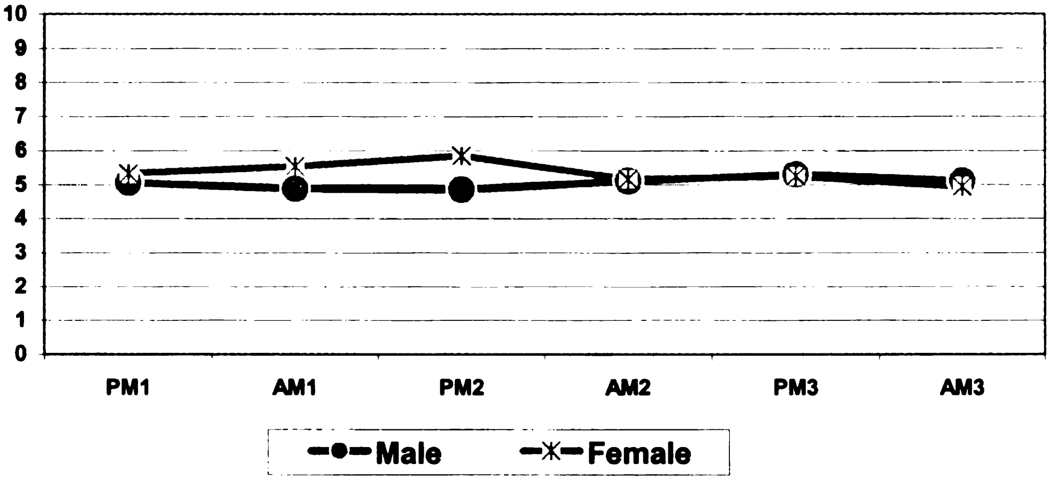
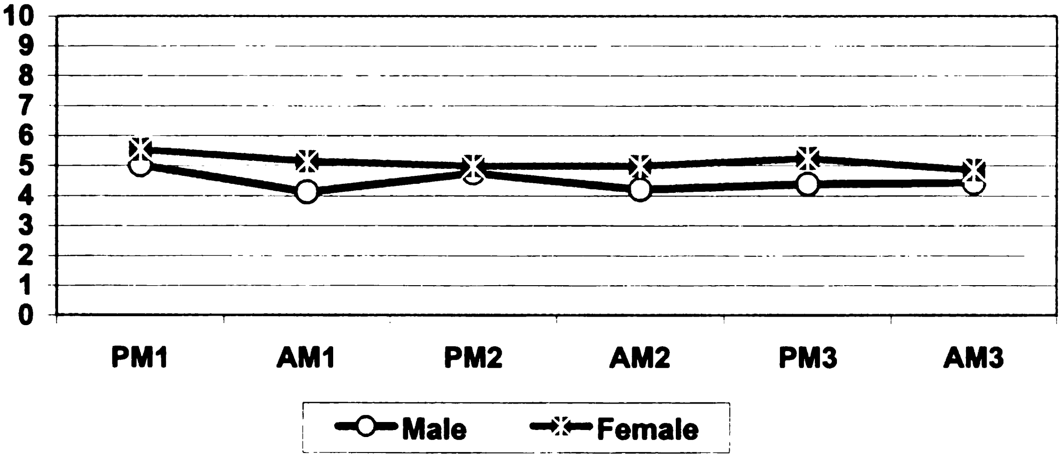


Fig 4. Morning and Evening Fatigue in Family Caregivers



Aim 4. Correlation between sleep disturbances and the other symptoms

1. Fatigue, Depression and Pain in Patients and Family Caregivers

The fatigue, depression, pain and quality of life data, as reported by patients and family caregivers at the time of enrollment in the study, are listed in Tables 16, 17, 21. There were no significant differences in fatigue, depression and pain by cycle of chemotherapy. All patients reported moderate levels of fatigue as measured by the 13-itme Lee Fatigue Scale ($\bar{X}$=4.9, SD=1.75), but female patients felt more fatigue than male patients. Caregivers' scores were not significantly different from the patients, with female caregivers having a higher fatigue level as well.

Table 19. Fatigue and Depression Levels for Patients and Family Caregivers

			Fatigue	Depression
		N	Mean (SD)	Mean (SD)
Patients	Male	71	4.22 (2.02)	14.71 (8.58)
	Female	32	5.45 (1.47)	20.68 (9.06)
	Total	**103**	**4.60 (1.94)**	**16.57 (9.12)**
Family Caregivers	Male	23	3.77 (1.16)	13 (5.3)
	Female	80	5.15 (1.21)	19.58 (8.6)
	Total	**103**	**4.84 (1.33)**	**18.11 (8.4)**

The patients' depression scores ranged from 1 to 40 ($\bar{X}$=16.57, SD=9.12). Male patients ($\bar{X}$=14.7, SD 8.58) had a lower score than females ($\bar{X}$=20.7, SD=9.06). The caregiver's depression scores ranged from 3 to 44 ($\bar{X}$=18.1, SD=8.43) with male caregivers also showing a lower depression score ($\bar{X}$=13, SD=5.3) than females ($\bar{X}$=19.6, SD=8.6). Of the 103 patients in this study, 55 (53.4%) scored at or above the standard population cutoff of 16 for the CES-D, indicating that they were at risk for clinical depression. In the caregiver sample, 60 (58%) showed at or above the cutoff score of 16. These scores are summarized in Table 20. According to Cho, Nam, and Suh (1998), the cutoff score for evaluating clinically depressive symptoms for Koreans was 21. In this study, 33% of patients and 38% of family caregivers scored higher than 21 on the CES-D. The differences between patients' and caregivers' depression scores as well as gender differences will be described in a later section.

Table 20. Depression Scores by Gender of Patient and Family Caregiver

		CESD score		
		Lower than 16	16 to 21	Over 21
Patients	Male	40 (38.8%)	13 (12.6%)	18 (17.5%)
	Female	8 (7.8%)	8 (7.8%)	16 (15.5%)
	Total	**48 (46.6%)**	**21 (20.4%)**	**34 (33%)**
Caregivers	Male	18 (17.5%)	2 (1.9%)	3 (2.9%)
	Female	25 (24.3%)	19 (18.4%)	36 (35%)
	Total	**43 (43%)**	**21 (20.4%)**	**39 (37.9%)**

Table 21 and 22 shows the summary of pain sites in patients and family caregivers. There were not many patient complaints of pain although approximately 30% said they had pain in the past week and abdominal pain was the most common site mentioned. In the sample of family caregivers, 33% had pain, and the lower limb was the most common site.

Table 21. Presence of Pain Reported by Patient and Family Caregiver

	N	Yes	No
Patients	103	29 (28%)	74(72%)
Family Caregivers	103	34 (33%)	69 (67%)

Table 22. Pain Site by Patient and Family Caregiver

	Patients	Caregivers
	n	n
Head and neck	6	10
Shoulder	3	10
Arms	4	8
Chest	7	6
Abdomen	16	8
Legs	11	21
Upper back	3	5
Lower back	9	15
Pelvis	1	0

The global QOL scores are summarized in Table 23. The global QOL score for patients was 5.7 (SD= 0.58) and 5.8 (SD=0.51) for caregivers. There was a significantly higher score on the subscale of symptom distress for caregivers ($\overline{X}$ =8.4, SD= 1.71) compared to patients ($\overline{X}$ =7.4, SD=1.81).

Table 23. Quality of Life Reported by Patient and Family Caregiver

		Global QOL (range 0-10)		Psychological Well Being	General Physical Well Being	Nutrition Score	Symptom Distress	Interpersonal Well Being
Group	Gender	N	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Patients	Male	71	5.76 (0.59)	5.32 (1.33)	6.78 (1.30)	6.15 (1.72)	7.69 (1.69)	6.28 (1.30)
	Female	32	5.60 (0.56)	4.87 (1.49)	6.32 (1.38)	5.53 (1.54)	6.83 (1.93)	6.35 (1.14)
	Total	**103**	**5.71 (0.58)**	**5.18 (1.39)**	**6.64 (1.34)**	**5.96 (1.68)**	**7.42 (1.81)**	**6.30 (1.25)**
Family Caregivers	Male	23	5.94 (0.51)	5.49 (1.21)	7.39 (1.16)	5.85 (1.14)	7.82 (2.0)	6.50 (0.72)
	Female	80	5.75 (0.51)	4.87 (1.24)	6.92 (0.80)	5.54 (1.30)	8.53 (1.60)	6.26 (1.15)
	Total	**103**	**5.80 (0.51)**	**5.01 (1.25)**	**7.03 (0.91)**	**5.61 (1.27)**	**8.38 (1.71)**	**6.31 (1.07)**

A Paired sample *t*-test was conducted to compare fatigue, depression and quality of life between the patients and family caregivers. There were no statistically significant differences in fatigue, depression and quality of life (t(102)=-1.05, -1.23, -1.34, respectively). Noticeably, in both groups' symptom distress components scores were higher than any other components. Both groups reported very little symptom distress in relation to tiredness, pain, bowel movement (constipation and diarrhea), vomiting and nausea. Also, there was no correlation between patients and family caregivers except in the global quality of life scores. The global quality of life score was correlated in both groups (r=0.28, p<0.005). Tables 24 and 25 summarize these comparisons.

Table 24. Paired Samples *t*-Test: Comparing Symptoms of Patient and Family Caregiver

	Paired Differences					t	df	Sig.
	Mean	SD	Std. Error Mean	95% Confidence Interval of the Difference				
				Lower	Upper			
Fatigue	-.23	2.29	.22	-.68	.20	1.05	102	.29
Depression	-1.54	12.67	1.24	-4.02	.93	1.23	102	.21
QOL	-.08	.66	.06	-.21	.04	1.34	102	.18

Table 25. Paired Samples Correlations Between Patients and Family Caregivers

	N	Correlation	Sig.
Fatigue	103	.05	.59
Depression	103	-.04	.67
QOL	103	.28	<.001

An independent sample t-test was conducted to compare male and female fatigue, depression, and global quality of life measures. In the patients' group, there were statistically significant differences in fatigue (t (101)=-3.09, p<0.005) and depression (t(101)=-3.21, p<0.005) by gender. There was no significant difference by gender in global quality of life and its four subscales (i.e., psychological well being, physical well being, nutrition, and interpersonal well being) except symptom distress (t (101)= 2.27, p<0.05). For family caregivers, there were also significant differences in depression (t (101)=-3.48, p<0.001) and fatigue (t (101)=-4.86, p<0.001) scores between men and women. As in the patient group, there were also no statistically significant differences in global quality of life by gender for family caregivers, except in two subscales (i.e., psychological well being and physical well being), which were significantly differenced by gender (t (101)=2.09, p<0.05; t (101)=2.22, p<0.05). Tables 26 and 27 summarize these results.

Table 26. Gender Differences in Fatigue, Depression and Quality of Life for Patients

	t	Sig.	Mean diff	95% Confidence Interval of the diff	
				Lower	Upper
Fatigue	-3.08	<.001	-1.22	-2.01	-.43
Depression	-3.20	<.001	-5.96	-9.65	-2.27
QOL	1.30	.19	.16	-.084	.40
QOL Psychological well being Score	1.51	.13	.44	-.13	1.03
QOL Physical well being Score	1.62	.10	.46	-.10	1.02
QOL Nutrition Score	1.75	.08	.62	-.08	1.33
QOL Symptom distress Score	2.27	.03	.85	.10	1.60
QOL Interpersonal well being Score	-.25	.79	-.06	-.60	.46

Table 27. Gender Differences in Fatigue, Depression and Quality of Life for Family Caregivers

	t	Sig.	Mean Diff	95% Confidence Interval of the Difference	
				Lower	Upper
Fatigue	-4.85	<.001	-17.93	-25.26	-10.60
Depression	-3.47	<.001	-6.58	-10.34	-2.82
Quality of Life	1.50	.13	.18	-.058	.42
QOL Psychological well being Score	2.09	.03	.61	.03	1.19
QOL Physical well being Score	2.22	.02	.47	.05	.89
QOL Nutrition Score	1.03	.30	.31	-.28	.90
QOL Symptom distress Score	-1.77	.08	-.71	-1.51	.08
QOL Interpersonal well being Score	.94	.34	.24	-.26	.74

2. Correlation between demographic variables and symptoms

A. Patients and Family Caregivers

Bivariate correlation analysis using Pearson's product moment correlation coefficient (r) was employed to examine the relationships among patients' demographic characteristics, sleep disturbances, depression, and general fatigue. There were moderate negative correlations between several demographic variables and sleep problems in patients. Sleep disturbance, as measured by PSQI, was positively and significantly associated with age (r=0.29, p<0.01). Since perception of

health status, previous sleep problem and education were categorical variables; Spearman's rho was used to determine the correlations. The perception of health status was negatively correlated with sleep quality, fatigue, and depression (ρ=-0.24, $p<0.05$, ρ=-0.41, $p<0.01$, ρ=-0.34, $p<0.01$ respectively).

The caregivers' demographic variables, especially perception of health status, had a moderate negative correlation to sleep quality (ρ =-0.22, $p<0.05$), fatigue (ρ=-0.36, $p<0.001$), and depression (ρ=-0.39, $p<0.001$). Financial status was negatively correlated with sleep (r=-0.23, $p<0.01$), depression (r=-0.32, $p<0.01$), and fatigue (r=-0.30, $p<0.01$). Family caregiver's responsibility for caring for patients was negatively correlated with depression (r=-0.30, $p<0.01$). In both groups, patients and caregivers, the perception of health status was significantly negatively correlated with sleep, fatigue, and depression. The financial status was not correlated with any symptoms in the patients, but it was moderately correlated with symptoms in the caregivers. The summary of these correlations is showed in Table 28.

Table 28. Correlation of Demographic Variables and Symptoms

		AGE	EDU	FS	HS	R-F	R-P
Correlation coefficient		r	ρ	ρ	ρ	r	r
Patients	Sleep Quality	.29**	-.15	-.02	-.24*	-.13	
	Fatigue	0.05	-.18	.01	-.41**	-.01	
	Depression	0.08	-.13	-.07	-.34**	-.42	
Family caregivers	Sleep	.14	-.22*	-.23*	-.22*	.15	-.12
	Fatigue	.18	-.21*	-.32**	-.39**	.13	-.07
	Depression	.13	-.14	-.30**	-.39**	.18	-.30**

** $p<0.01$ *$p<0.05$

FS: Financial Status, HS: Health Status,

R-F: Responsibility of caring for family, R-P: Responsibility of caring for patient

B. Correlations among symptoms: Patients

The patients group had a moderate positive correlation between depression and fatigue ($r=0.44$, $p<0.01$), and sleep and depression ($r=0.21$, $p<0.05$). There was no significant correlation between sleep and AM or PM fatigue. Fatigue and depression were negatively correlated with QOL ($r=-0.43$, $p<0.005$; $r=-0.56$, $p<0.005$), but there was no significant relationship between sleep quality and QOL in patients ($r=-0.14$, $p=0.17$). The correlation matrix is summarized in Table 29.

Since gender has been a moderator for symptoms, which may affect the direction and/or strength of the relation between an independent variable and dependent variable, it was necessary to control for gender in assessing the correlation of between symptoms. Partial correlations were used to explore the relationship

between sleep and depression, while controlling for gender. Preliminary analyses were performed to ensure there was no violation of the assumption of linearity and homoscedasticity. There was a small, positive, partial correlation between sleep and depression (r=0.19, n=100, p=0.05) after controlling for gender. An inspection of the zero order correlation (r=0.21) suggested that controlling for gender had very little effect on the strength of the relationship between sleep and depression. The partial correlation of fatigue and depression, while controlling for gender, was a medium, positive partial correlation (r=0.39, n=100, p<0.005), but the zero order correlation (r=0.44) suggested that controlling for gender had little effect on the strength of the relationship between fatigue and depression.

C. Correlations among Symptoms: Family Caregivers

Depression, fatigue, and sleep were positively correlated with each other in the caregiver group (r=0.33, p<0.01), and these variables were negatively correlated with global QOL (r=-0.49, -0.45, -0.34 respectively, p<0.01).

Partial correlation was also used to explore the relationship of sleep, depression, and fatigue in family caregivers, while controlling for gender. There were medium, positive, partial correlations between sleep and depression (r=0.33, n=101, p=0.001), sleep and fatigue (r=0.32, n=101, p=0.001), and fatigue and depression (r=0.33, n=101, p=0.001). An inspection of the zero order correlation (r=0.21) suggested that controlling for gender had very little effect on the strength of the relationship between sleep and depression. The partial correlation of fatigue and depression, while controlling for gender, was a medium, positive partial correlation (r=0.39, n=100, p<0.005), but the zero order correlation (r=0.44) suggested that controlling for gender had little effect on the strength of the relationship between fatigue and depression in caregivers.

Table 29. Correlations among Sleep, Fatigue, Depression, and Quality of Life

Group		Depression	Sleep	Fatigue	QOL
PATIENTS	Depression	1			
	Sleep	.21(*)	1		
	Fatigue	.44(**)	.17	1	
	QOL	-.56(**)	-.14	-.43(**)	1
CAREGIVERS	Depression	1			
	Sleep	.33(**)	1		
	Fatigue	.33(**)	.32(**)	1	
	QOL	-.49(**)	-.34(**)	-.45(**)	1

* Correlation is significant at the 0.05 level (2-tailed).

** Correlation is significant at the 0.01 level (2-tailed).

Aim 5: Predictors of Quality of Life

1. Patients

The relationships between demographic variables and symptoms and between symptoms and quality of life are presented in Table 29. Based on these correlations, the following variables were selected because of their intercorrelation, and a multivariate approach was used to evaluate the combined and individual contributions of the symptoms and demographic variables to quality of life. A series of hierarchical regression analyses were conducted in which the variables were entered in sets consisting of demographic variables (i.e., gender, financial status, and perception of health status) and symptoms (i.e., sleep, depression, fatigue).

After the variables in block 1 (selected demographic variables) were entered, three demographic variables (i.e., gender, financial status, and health status) together account for 21.7% of variance in patient quality of life. Adding the set of three symptom variables (i.e., sleep quality, fatigue, and depression) in block 2 increase R^2 square by 20.8%. Looking at the model as a whole, 43% of variance in quality of life was explained by both blocks of variables (F (6,96)=11.82, $p<0.005$). There were three variables that made a statistically significant contribution ($p<0.05$): in order of importance: financial status ($Sr^2=0.04$), health status ($Sr^2=0.04$), and depression ($Sr^2=0.13$). Gender, global sleep quality and fatigue did not add anything to the model when controlling for the other three variables. The summary of multiple regression analysis follows in Table 30.

Table 30. Multiple Regression Analysis: Dependent Variable, Patient Quality of Life (N=103)

Model	Variables	R^2 change	Df	Beta	F value	P value	Sr^2
1	Overall	**.22**	3		9.14		
	Gender		1	.01	00	.90	.01
	Health Status		1	.42	20.25	<.001	.16
	Financial Status		1	.27	8.70	<.001	.07
2	Overall	**.43**	6		11.82		
	Gender		1	.13	2.46	.12	.01
	Health Status		1	.24	7.13	<.001	.04
	Financial Status		1	.19	6.10	.01	.04
	Fatigue		1	-.17	3.50	.06	.02
	Depression		1	-.42	21.90	<.001	.13
	Sleep Quality		1	.02	.07	.78	.00

2. Family Caregivers

After the variables in block 1 (selected demographic variables) were entered, the overall model explained 33% of the variance in caregiver's quality of life. After block 2 (symptoms) was included, the model as a whole explained 43%. The model as a whole, when including both blocks of variables, was significant (F (6,96)=12.26, $p<0.005$).

There were two variables in the demographic profile and two symptoms that made a statistically significant contribution ($p<0.05$). In order of importance, they were: financial status ($Sr^2=0.03$), health status ($Sr^2=0.04$), depression ($Sr^2=0.06$) and fatigue ($Sr^2=0.04$). In both patients and caregivers, depression was the largest unique contribution to the variance in quality of life. The summary of multiple

regression analysis for caregivers follows in Table 31.

Table 31. Multiple Regression Analysis: Dependent Variable, Family Caregivers Quality of Life (N=103)

Model		R^2	dF	Beta	F	P value	Sr^2
1	Overall	**.33**	3,99		16.28		
	Gender		1	-.041	.23	.62	.00
	Financial Status		1	.308	13.39	<.001	.09
	Health Status		1	.416	23.81	<.001	.16
2	Overall	**.43**	6,96		12.26		
	Gender		1	.114	1.58	.20	.00
	Financial status		1	.180	4.49	.03	.03
	Health status		1	.252	7.72	<.001	.04
	Depression		1	-.283	9.42	<.001	.06
	Fatigue		1	-.244	6.25	.01	.04
	Sleep		1	-.023	.06	.79	.00

Summary

For this study, the sample consisted of 103 dyads that included both patient and family caregiver. Instruments used in this study were internally consistent with Cronbach alpha coefficients, between 0.69-0.90. There was no difference in any variable (i.e., sleep quality, fatigue, depression, and quality of life) by cycle of chemotherapy. Global sleep quality was the only variable statistically different between patients and family caregivers. There were no significant differences in depression, fatigue and quality of life between patients and their caregivers.

Approximately one third of the patients went to bed with severe fatigue, followed by similar complaints of morning fatigue, which may demonstrate that for this sample sleep did not resolve their fatigue. More than 80% of patients and 50% of family caregivers woke up during the night.

There were gender differences in each group for depression and fatigue, but not in global quality of life subscales, and global sleep quality. Selected demographic variables such as age, gender, perception of health status, and previous sleep problems were moderately associated with fatigue, depression and quality of life. In family caregivers, gender, education, financial status, perception of health status, previous sleep problems, and responsibility for caring for the patients were from mildly to moderately correlate with fatigue, depression and sleep. Responsibility for caring for the patients was moderately correlated with only depression in the family caregiver. Financial impact was not correlated with patients' fatigue, depression and sleep, but it was moderately correlated for caregivers in all three areas.

The patients group had a moderate positive correlation between depression and fatigue ($r=0.44$, $p<0.01$), and sleep and depression ($r=0.21$, $p<0.05$), although there was no significant correlation between sleep and fatigue. Fatigue and depression were negatively correlated with QOL ($r=-0.43$, $p<0.005$; $r=-0.56$, $p<0.005$), but there was no significant relationship between sleep quality and QOL ($r=-0.14$, $p=0.17$). The three study variables were positively correlated with each other for the family caregivers. Depression, fatigue, and sleep were significantly correlated ($r=0.33$, $p<0.01$), and these variables were negatively correlated with QOL ($r=-0.49$, -0.45, -

0.35 respectively, $p<0.01$).

Multiple regression analysis revealed that the selected demographic variables and symptoms explained 43% of the variance in global quality of life in both patients and caregivers, with the large proportion of the variance explained by depression, perception of health status and financial status in the patient group. For family caregivers, however, it was financial status, perception of health status, fatigue, and depression.

CHAPTER V

DISCUSSION

Introduction

This chapter will be organized as follows. First, there will be an interpretation of the major findings of this study, and results will then be compared to other studies. Second is a discussion of the limitations of this study. Finally, the implications for oncology nursing and recommendations for further research will be presented.

Major Findings

The primary purpose of this study was to examine sleep variables in gastric cancer patients who were receiving chemotherapy, and compare their sleep with those of their family caregiver. This study made an important contribution to new knowledge as it documented the pattern and characteristics of sleep and correlated factors of sleep quality for gastric cancer patients and their caregivers. This new information can guide development and testing of future management strategies.

Approximately 85% of the patients and 80% of family caregivers scored greater than 5 on self-reported PSQI global sleep quality, which indicated poor sleep. The PSQI has been used in many different clinical populations and Table 32 below compares the PSQI scores of this sample with other patient groups. The global score was lower than scores for depressed or psychiatric problem patients but similar to

Carpenter's population of breast cancer women.

Doi et al's (2000) study in a Japanese sample used a cutoff score of 5.5. In this study, if the researcher used Doi's cutoff score for the Korean present sample, 69% of patients and 51% of caregivers would have a score higher than 5.5. Even after employing Carpenter and Androwski's (1998) suggestion of a cutoff score of 8 for the cancer patient when indicating poor sleep quality.; 37% of the Korean patients scored higher than 8. One of the interesting components in PSQI was the use of sleep medication. Use of sleep medication in this study was similar to Carter's study (2000) where she found that several caregivers were prescribed sleep medication, but that they were reluctant to take it because it interfered with their ability to monitor and care for the patient at night. In this study, the reason for not taking medication is based on cultural beliefs around using sleeping pills. In Korea, it is not common to use sleeping pills to help sleep.

In the three-day sleep diary, neither patient nor caregiver showed any changes over the three days. They both had long sleep latency and difficulty and maintaining sleep. The chemotherapy cycle the patient was on did not affect these patterns. These diaries showed that morning and evening fatigue in patients and caregivers did not change much, which suggests that sleep might not be helpful in alleviating their morning fatigue.

Table 32. Comparing PSQI Global Score

*cutoff score: suggested cutoff score for indication of poor sleep

Author	Year	Sample N	Sample	*Cutoff score	Global score
Buysse	1988	52	Healthy (U.S.)	5	2.7
Buysse	1988	54	Depressed(U.S.)		11.1
Buysse	1988	45	Sleep disorder patients(U.S.)		10.4
Carpenter	1998	57	BMT women(U.S.)		6
Carpenter	1998	98	BMT men(U.S.)		5.4
Carpenter	1998	30	Renal transplant women(U.S.)		7.9
Carpenter	1998	26	Renal transplant men(U.S.)		7.3
Carpenter	1998	102	Breast cancer women(U.S.)	8	7
Carpenter	1998	159	Benign breast problem(U.S.)		6.4
Owen	1999	15	Cancer(U.S.)		6.7
Doi	2000	82	Healthy (Japanese)	5.5	3.8
Doi	2000	14	Primary insomnia(Japanese)		8.9
Doi	2000	30	Major depression(Japanese)		9.3
Doi	2000	24	Generalized anxiety(Japanese)		9.6
Doi	2000	24	Schizophrenia(Japanese)		9.1
Carter	2000	51	Cancer caregivers(U.S.)		11.3
Cho	2003	103	Gastric cancer (Korean)		6.9
Cho	2003	103	Cancer caregivers (Korean)		5.8

Gender had no effect on sleep quality or quality of life for either patients or family caregivers. But in both groups, there were statistically significant differences in fatigue severity and frequency of depressive symptoms by gender. Regarding depressive symptoms, male patients had a lower depression score than females, which is consistent with another study (Silberstein, 1999). There were also gender differences in depression scores in caregivers with female caregivers, reporting a higher depression score than males which is different than Carter's (2003) findings.

Over half the patients in the present study were at risk for clinical depression. Of the 103 patients in this study, 55 (53.4%) scored at or above the standard population cutoff of 16, while 58% of caregivers were over 16, indicating that they were also at risk for clinical depression. Applying Cho and Kim (1998)'s cutoff score of 21 for Koreans, 33% patients and 38% caregivers scored higher than 21 in the CES-D. Cho and Kim (1998) explained that there was no clear explanation for the high scores, but there are certain possible explanations. One of these may be the low socioeconomic strata. Despite considerable economic growth during the past decade in Korea, the socioeconomic level of Korea is still lower than that of advanced Western countries (Cho & Kim, 1998). For instance, African Americans and other minorities of relatively lower socioeconomic class showed more pronounced depressive symptoms and higher scores than the White middle class (Cho et al., 1993; Moscicki et al., 1987). Cho and Kim (1998) also suggested that Koreans' methods of expression, based on Confucian thought, can lead to the higher scores on the CES-D. Koreans tend to express positive feelings verbally via the influence of Confucian culture (Cho & Kim, 1998). In Confucian culture, it is not considered socially acceptable to openly express or reflect negative emotions, but study participants were more likely to express feelings of depression when using self-administered paper and pencil questionnaires (Cho & Kim, 1998; Kim, Chung, & Choi, 1992; Noh, Avison, Kaspar, 1992). The researcher also had a similar experience when collecting data from patients and family caregivers.

Female patients and female family caregivers had significantly higher fatigue than male patients and male family caregivers. The mean level of fatigue (4.84) in caregivers of this study is higher than that found by Teel and Press (1999) who used the Lee Fatigue Scale to measure fatigue level in cancer caregivers and their mean level of fatigue was 3.32. The Teel and Press (1999) finding is similar to several other studies that measured fatigue (Heinonen et al., 2001; Pater, Zee, Palmer, Johnston, & Osoba, 1997).

There were no statistically significant differences in fatigue, depression and quality of life between these two groups. Also, there was little correlation between patients' and family caregivers' fatigue and depression except in quality of life scores ($r=0.28$, $p<0.005$) which may show that the fatigue and depression level of the patient is independent of the caregiver's fatigue and depression level and vice versa. However, the patients' quality of life scores was not independent of the family caregivers' which may explain that quality of life as a global concept was more important and had more impact than the individual symptoms of fatigue and depression.

For the caregivers, QOL can be explained by 43% of the variance in selected demographic variables and three symptoms (i.e., sleep, fatigue, and depression).

However, 33% of the variance was explained by selected demographic variables (financial and health status), while three symptoms only added 10% to the variance. This is different from the patient group, where the patients showed approximately an equal amount of contribution from their symptoms and selected demographic variables in QOL variance. In other studies of the impact of chronic illness on caregivers (Choi, 1993; Kim and Lee, 2003), the significant contribution of demographic variables to the variance was also noted. This result may reflect the lack of social support and infrastructure in Korea to meet the financial and health needs of caregivers.

Another finding was that in both groups, frequency of depressive symptoms was the largest unique contributor to quality of life ($sr^2=0.13$ in patients and $sr^2=0.06$ in caregivers). This finding for caregivers has been supported by several studies (Carter & Chang, 2000; Carter 2002; Carter, 2003; Kim and Lee, 1998). There were similar findings for patients in Gaston-Johansson's (1999) report that depression and pain accounted for 64% of variance in perception of health status, and fatigue and depression accounted for 42% of the variance in health status in breast cancer patients who had completed chemotherapy treatment. Redeker et al. (2000) also reported that depression and anxiety accounted for 43% of the variance in quality of life for patients who were receiving chemotherapy.

Finally, sleep disturbance was a highly prevalent problem for gastric cancer patients and their family caregivers. There were several risk factors for developing sleep disturbance and lowering the quality of life: 1) demographic variables of financial status, perception of health status, gender and 2) symptoms of fatigue and depression.

Limitations of the Study

The limitations of this study will be discussed before generalizing the results. Although this study provided an important first description of sleep disturbance for gastric cancer patients and their family caregivers, the limitations include study design, instruments, and generalizability. First, the cross sectional and correlational design of this study, cannot establish causal relationships from data collected in a cross-sectional time frame (Newman, Browner, Cummings, & Hulley, 2001). Also, there was no contrast or control group with which to compare the study population.

The second limitation of this study is that the retrospective assessment of sleep history can leave out information due to memory lapse. Unfortunately, there were some missing data noted in the sleep diaries. The lack of objective measurements of sleep is another weakness. Objective sleep measures, such as actigraphy, can be used to accurately describe the sleep-wake circadian cycle as well as sleep characteristics in cancer patients and caregivers. Subjective measurements can be more reliable in

certain aspects of sleep quality, especially when it comes to verbalizing one's perception of that quality (Cohen, 1997; Engstrom et al., 1999; Johns, 1971). Therefore, many sleep researchers have concluded that subjective and objective measurements are complementary and must be used together to obtain more accurate and precise sleep data (Cohen, 1997).

In future studies, incorporating a measurement of the caregivers' burden into the study would be useful. In this study, only one item in the demographic questionnaire asked about the responsibility of currently taking care of the patients. The mean score of responsibility was over 80% (range 0-100%). Comparing the nuances of the two words, burden and responsibility, may enrich findings in future studies. This study did not measure the cultural aspects of familism, although there is a strong value of familism in Korea when planning to care for an ill member of the family. Further study is needed to measure the cultural aspects of familism in family caregivers in Korea.

Implications of the Findings for Nursing

Although it is essential for all humans, sleep may be especially important for those who bear the burden of illness such as cancer patients and their caregivers. The study results provide strong support for the presence of sleep disturbance in gastric cancer patients and their family caregivers. Selected demographic variables (i.e., financial impact, perception of health status, previous sleep problem) are significantly correlated with unpleasant symptoms and a lower quality of life for the caregiver group. These above mentioned variables, along with gender, were also moderately correlated in the patient group and could be used by the nurse when assessing sleep disturbance for each patient and their caregiver.

Oncology nurses are in an ideal position to enhance sleep for patients and their family caregivers using appropriate assessment and management strategies. Family members usually are eager to address physical problems (e.g., loss of appetite, fatigue, pain) and provide routine care (e.g., administering medication, treatment visit, bathing), but the role of family caregivers is multifaceted and variable (Duhamel & Dupuis, 2004). According to Schulz, Visintainer, & Williamson (1990), the innumerable tasks of caregiving often lead to "self-neglect" which in turn results in caregiver fatigue.

The burden of caring for cancer patients in Korean society is aggravated by the fact that accepting personal care from a non-family member is discouraged (Kim & Lee, 2003). The lack of availability of an infrastructure for in-home service or community-based supports places tremendous pressure on family caregivers which is aggravated by social changes in family structure in 21st Century Korean society. These changes include greater female participation in the paid labor force outside the home,

a decrease in multigenerational households and family size, the geographical mobility of the young and the weakening of traditional cultural values in the family (Choi, 1996; Kim & Lee, 2003). With the aging of the population and the increasing number of individuals being diagnosed with advanced cancer, family caregivers are being pushed into assuming a greater role in caring for patient needs (Carter 2002).

Caregivers of patients with cancer experience fatigue, depression, sleep disturbance and risk to their health status, as well as incurring a financial burden. Therefore, health care professionals need to develop risk profiles to anticipate which family members are likely to experience symptoms and then plan for services to support them. For instance, including a question about previous sleep problems in the nursing assessment of the patient and their family caregiver when they come to the clinic for treatment, and whether they had been experiencing any sleep problems, will aid the oncology nurse in recognizing the need to provide further assessment and management. As more families are becoming involved in the health care of their ill members, nursing must move from patient centered to family centered nursing (Wright & Leahey, 1990).

Recommendations for Further Research

To date, research on cancer patients has explored the prevalence of sleep disturbance and reported its relationship to other symptoms. A few descriptive studies have been reported on family members of a person with cancer to assess the presence of sleep disturbance. There are several things to consider for future research.

The first point to consider for future research is to observe patients and caregivers for longer periods of time to see the changes over time in their sleep patterns and other symptoms. Sleep must be understood as a continuous phenomenon, so that variations in the sleep pattern during the course of an illness may be more fully understood. It is necessary to determine each individual's sleep and wake cycle in order to help the clinician decide on the timing of an intervention that may reduce side effects and improve the quality of life. According to Mormont and Levi (1997) specific knowledge of altered circadian rhythms in cancer patients would serve as a valuable prognostic tool in large clinical trials for improving each patient's response to treatment. In addition, better circadian rhythm function may be one of the biological determinants of quality of life for cancer patients (Mormont & Waterhouse, 2002).

The second point to consider for future research is that an objective method should be used to determine patients' sleep patterns. There are few studies that objectively investigate the extent and severity of sleep disturbances in cancer patients (Berger & Farr, 1999; Mormont & Levi, 1997; Miaskowski & Lee, 1999; Silberfarb et al., 1993). Earlier technology that objectively measured sleep was limited to polysomnography (electroencephalogram, electro oculogram, and electromyelogram), which is expensive, uncomfortable and inconvenient for routine use in clinical practice (Fontaine, 1989). Recently, wrist actigraphy has proven to be a valid and reliable method to measure and evaluate sleep disturbances in cancer patients (Miaskowski & Lee, 1999; Mormont et al., 1995; Mormont & Levi, 1997). Another benefit of the wrist actigraph is that it is not invasive and may be used with vulnerable and fragile cancer patients. Although this instrument has limitations in distinguishing patients who have been lying awake and not moving versus actually being asleep, it is a valuable instrument in clinical practice for measuring sleep problems in patients with cancer (Miaskowski & Lee, 1999).

Thirdly, it is important for developing and testing a biomarker of sleep disturbance in patients and caregivers to determine the long term effects of cancer on patients and caregivers. Previous reports showed that family caregivers continuously had a high level of IL-6 in serum testing even after the patients had died (Kiecolt-Glaser et al., 2003). Greenberg's study (1992) suggested that there was an association between serum levels of interleukin-1 (IL-1), fatigue, and sleep. An elevated serum level of IL-1 was noted at the same time that the relative fatigue rating increased and fewer sleep hours were reported. However, these studies should be replicated and enlarged to corroborate these assertions.

Finally, testing the efficacy of interventions for sleep disturbances in cancer patients and family caregivers is highly recommended. The present study of Korean gastric cancer patients and their family caregivers only utilized two components of the Symptom Management Model: symptom experiences (i.e., sleep, fatigue, depression) and symptom outcomes (Quality of Life). Future studies need to develop innovative strategies of alleviating symptoms and increasing quality of life. In addition, management strategy should be culturally integral and receptive to change the outcome of symptom status and quality of life. For example, since caregivers are afraid to use sleeping pills as they may interfere with the caring activity (Carter & Chang, 2000), it would be useful to test several non-pharmacological methods. Non-pharmacologic approaches include educating the patient and family members about sleep hygiene and cognitive behavioral techniques (e.g. meditation, guided imagery, hypnosis, progressive muscle relaxation training), which have been proven to be effective methods of treating cancer-related insomnia. In addition, these methods are safe alternatives to sleep medication, and appropriate for long-term insomnia (Mendelson, 1987; Morin, Culbert, & Schwartz, 1994; Morin, Colecchi, Stone, Sood, & Brink, 1999).

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APPENDIX A-Demographic Questionnaire

For office use only : ID#

Instruction: For each of following questions, please either fill in the blank or circle the appropriate response, depending on the question. For each question, please select the one best response, unless otherwise indicated

1. Date of Birth: ____________________/_____________/_____________
   Year Month Day
2. Gender: Man __________ Woman ___________
3. Height:_______________ cm
4. Weight: ______________kg
5. Circle the number that describes your current marital status?
   1) married
   2) Not married but living together
   3) Widowed
   4) Divorced
   5) Separated
   6) Never married
6. Circle the highest grade or year you completed in regular school, vocational school , college, or graduate professional training (circle one number only)

   Elementary 1 2 3 4 5 6
   Middle school 1 2 3
   High school 1 2 3
   College Graduate 1 2 3 4
   Graduate School 1 2 3 4

7. Current employment status
    1) Employed full time
    2) Employed part time
    3) Unemployed
    4) Retired
    5) Homemaker
    6) Unable to work because of health
    7) Student
    8) Other
8. Since the cancer diagnosis of your spouse, have you made any changes in your employment?
    1) Yes
    2) No
9. Your current financial status is
    1) Barely surviving
    2) Getting behind
    3) Breaking even
    4) Moderately well off
    5) Very well off
10. Do you have financial difficulty because of your spouse's illness?
    1) Yes
    2) No
11. How much financial responsibility would you say you have for the family members?

0%	10 %	20 %	30 %	40 %	50 %	60 %	70 %	80 %	90 %	100 %

12. How much responsibility would you say currently have for your family (eg., as a household, or as a father or mother)?

0%	10 %	20 %	30 %	40 %	50 %	60 %	70 %	80 %	90 %	100 %

13. Please specify the current monthly income for your household
    1) less than 500,000 Won
    2) 500,000-1,000,000 Won
    3) 100,000-150,000 Won

4) 1,500,000- 2,000,000 Won
5) 2,000,000 Won or over

14. Mark an X in the box next to the statement that best describes your abilities at the present time:
    1) I feel normal; I have no complaints or symptoms
    2) I am able to carry on normal activities; I have minor signs or symptoms of my illness
    3) It takes a bit of effort to do my normal activity
    4) I can care for myself, but unable to carry on normal activity or to do active work
    5) I require occasional assistance, but am able to care for most of my personal needs
    6) I require a large amount of assistance and frequent medical care
    7) I require special care and assistance
    9) I feel severely disabled and need to be hospitalized

15. Have you had any sleep problem before?
    1) Yes
    2) No

if yes, please describe?

15a. When: ______________________________

15b. How often__________________________

15c. How long___________________________

15d. Did you use any remedies to help your sleep (e.g., tea, medication, massage etc)?

____

16. Where do you live in? Please circle the number of rooms in your house or apartment.

16a.

Apartment___________ House_______________

16b. Is your place noisy or quiet (living environment)?

Quiet________________ Noisy_______________ if your place is noisy, please describe the reason

____

____

____

17. Which food does your spouse prefer to eat during the chemotherapy?

____

Why?____

18. Which food does your spouse dislike during the chemotherapy?

____

Why?____

19. Have you even taken melatonin?
    1) Yes
    2) No

20. What medication are you taking currently ?
    1) Yes
    2) No

    Please list

	Name of medicine	How many times a day
1		
2		
3		
4		
5		
6		
7		

APPENDIX B-FAMILY CAREGIVERS

Demographic Questionnaire

For office use only : ID#

Instruction: For each of following questions, please either fill in the blank or circle the appropriate response, depending on the question. For each question, please select the one best response, unless otherwise indicated

1. Date of Birth: ____________________/______________/______________
Year Month Day

2. Gender: Man __________ Woman ___________

3. Height:_______________ cm

4. Weight: ______________kg

5. Circle the number that describes your current marital status?

7) married
8) Not married but living together
9) Widowed
10) Divorced
11) Separated
12) Never married

6. Circle the highest grade or year you completed in regular school, vocational school , college, or graduate professional training (circle one number only)

Elementary 1 2 3 4 5 6
Middle school 1 2 3
High school 1 2 3
College Graduate 1 2 3 4
Graduate School 1 2 3 4

7. Current employment status

10) Employed full time

11) Employed part time
12) Unemployed
13) Retired
14) Homemaker
15) Unable to work because of health
16) Student
17) Other

8. Since the cancer diagnosis of your spouse, have you made any changes in your employment?

3) Yes
4) No

9. Your current financial status is

6) Barely surviving
7) Getting behind
8) Breaking even
9) Moderately well off
10) Very well off

10.Do you have financial difficulty because of your spouse's illness?

3) Yes
4) No

11.How much responsibility would you say you have for the actual care of your spouse?

0%	10 %	20 %	30 %	40 %	50 %	60 %	70 %	80 %	90 %	100 %

12. How much responsibility would you say currently have for your family?

0%	10 %	20 %	30 %	40 %	50 %	60 %	70 %	80 %	90 %	100 %

13. Please specify the current monthly income for your household

6) less than 500,000 Won
7) 500,000-1,000,000 Won
8) 100,000-150,000 Won
9) 1,500,000- 2,000,000 Won
10) 2,000,000 Won or over

14. Mark an X in the box next to the statement that best describes your abilities at the present time:

1) I feel normal; I have no complaints or symptoms

2) I am able to carry on normal activities; I have minor signs
or symptoms of my illness

3) It takes a bit of effort to do my normal activity

4) I can care for myself, but unable to carry on normal activity or to do active work

5) I require occasional assistance, but am able to care for most of my personal needs

6) I require a large amount of assistance and frequent medical care

7) I require special care and assistance

18) I feel severely disabled and need to be hospitalized

15.Have you had any sleep problem before?

1) Yes
2) No

if yes, please describe?

15a. When: ______________________________

15b. How often__________________________

15c. How long___________________________

15d. Did you use any remedies to help your sleep
(e.g., tea, medication, massage etc)?

____

16.Where do you live in? Please circle the number of rooms in your house or apartment.

16a.

Apartment___________ House_______________

16b. Is your place noisy or quiet (living environment)?

Quiet________________ Noisy_______________ if your place is noisy, please describe the reason

____

____

____

17.Which food does your spouse prefer to eat during the chemotherapy?

____

Why?______________________________________

18.Which food does your spouse dislike during the chemotherapy?

____

Why?______________________________________

19.Have you even taken melatonin?

1)Yes

2)No

20.What medication are you taking currently ?

1)Yes

2)No

Please list

	Name of medicine	How many times a day
1		
2		
3		
4		
5		
6		
7		

Symptom Experiences Checklist

Are you currently experiencing any of the following symptoms?

Please X the number for each symptom that best describes how severe each symptom is for you.

	Yes	No	How often
SYMPTOM			
Dry mouth			
Thirst			
Taste changes			
Smell changes			
Difficulty swallowing			
Sores in mouth			
Lack appetite			
Weight loss			
Nausea			
Vomiting			
Feeling bloated			
Constipation			
Diarrhea			
Pain			
Headaches			
Dizziness			
Difficulty in concentration			
Numbness or tingling in hands or feet			
Itching			
Skin sensitive to sun			
Eyes sensitive to light			
Mood changes			
Cough			
Shortness of breath			
Memory problems			
Sleep problems			
Other or others, please specify			

APPENDIX C
SLEEP DIARY

First Evening

(Complete this section before going to sleep)

1. Today's date:____________________ Time:_________________AM/PM
2. Did you take any naps today?

    Yes _____ No______

If yes, what times and where did you nap (in bed, on sofa, in chair, in car, etc)

Nap #1: from _________
to ___________
location: _________________

Nap #2: from _________
to ___________
location: _________________

3. Today I did:
    1) no activity
    2) basic activity (light housekeeping, running errands, etc.)
    3) mild exercise (walking, isometrics, etc.)
    4) moderate exercise (heavy housework, gardening, etc.)
    5) strenuous exercise (jogging, swimming, etc.)
4. Today I ate:
    1) my usual diet
    2) an unusual diet, describe:________________________
5. Today I ate:
    1) my typical amount
    2) less than usual
    3) more than usual
6. what alcohol or caffeine beverages did you consume today?

examples(coffee, cola, tea)	type of beverage	time to consume

7. Did you encounter any particular stress today?

    yes _____ no_____

What, if any, problems did you experience today?
please describe___________________________

Not at all tired	0	1	2	3	4	5	6	7	8	9	10	Extremely tired
Not at all sleepy	0	1	2	3	4	5	6	7	8	9	10	Extremely sleepy
Not at all drowsy	0	1	2	3	4	5	6	7	8	9	10	Extremely drowsy
Not at all worn out	0	1	2	3	4	5	6	7	8	9	10	Extremely worn out
Concentrating is no Effort at all	0	1	2	3	4	5	6	7	8	9	10	Concentrating is no effort at all
Keeping my eyes open is no effort	0	1	2	3	4	5	6	7	8	9	10	Keeping my eyes open is a tremendous chore
I have absolutely no desire to lie down	0	1	2	3	4	5	6	7	8	9	10	I have absolutely no desire to lie down

First Morning

Today's Date:

Time:____________________AM/PM

1. Last night, I went to bed at ________________________pm
2. Falling asleep took _______________minutes, which was
   1) No time at all
   2) Not the usual amount of time
   3) Longer than usual
   4) Way too long
3. I awoke ______________time(s) during the night.
   1) What awakened you? ________________________
   2)Were any awakenings longer than 5 minutes?
   Yes_______ No_______
4. The number of awakenings was:_____________________________
5. The time spent awake was:_____________________________
6. I awoke this morning

At ____________AM

Got up at ____________AM

7. I feel
   1) Very alert
   2) Alert
   3) Somewhat drowsy
   4) Very drowsy
8. I feel
   1)Very rested
   2) Rested
   3) Somewhat rested
   4) Not at all rested
9. My sleep was
   1) Very poor
   2) Poor Fair
   3) Fair
   3) Good
   4) Very good
10. I dreamt
    1) Not at all
    2) Very little

3) A normal amount
4) More than usual
5) Don’t remember

Please circle the appropriate response, depending on the questions.

Not at all tired	0	1	2	3	4	5	6	7	8	9	10	Extremely tired
Not at all sleepy	0	1	2	3	4	5	6	7	8	9	10	Extremely sleepy
Not at all drowsy	0	1	2	3	4	5	6	7	8	9	10	Extremely drowsy
Not at all Worn out	0	1	2	3	4	5	6	7	8	9	10	Extremely worn out
Concentrating is no Effort at all	0	1	2	3	4	5	6	7	8	9	10	Concentrating is no effort at all
I have absolutely no desire to close my eyes	0	1	2	3	4	5	6	7	8	9	10	I have absolutely no desire to close my eyes
I have absolutely no desire to lie down	0	1	2	3	4	5	6	7	8	9	10	I have absolutely no desire to lie down

APPENDIX D

Pittsburgh Sleep Quality Index

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 months. Please answer all questions.

During the past months.

1. When you have usually gone to bed at night? ________________________
2. How long (in minutes) has it usually take you to fall asleep each night? __________________
3. When have you usually gotten up in the morning? ____________________________
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 spend in bed.)________________________

5.During the past month, how often have you had trouble sleep because you….	Not during The past month	Less than once a week	Once or twice a week	Three or more times a week
a) Cannot get to sleep within 30 minutes				
b) Wake up in the middle of the night or early morning				
c) Have to get up to use the bathroom				
d) Cannot breathe Comfortably				
e) Cough or snore loudly				
f) Feel too cold				
g) Feel too hot				
h) Had bad dreams				
i) Have pain				

J)Other reason(s), please describe, including, How often during the Past month have you had trouble sleeping because of this				
K) descriptions				
6.During the past month, how often have you taken medicine (prescribed or "over the counter") to help you sleep?				
7.During the past month, how often have you had trouble staying awake while driving, eating me engaging in social activity?				
8.During the past month, how much of a problem has it you to keep up enthusiasm things done?				
	Very good (0)	Fairly Good (1)	Fairly Bad (2)	Very bad (3)
9.During the past month, how would you rate your sleep quality overall?				

10. Do you have a bed partner or roommate?

☐ No bed partner or roommate

☐ Partner/roommate in other room

☐ Partner in same room, but not in the same bed

☐ Partner in same bed

11. If you have a roommate or bed partner,
how often during the past month,
did he/she cause you to have difficulty sleeping
because of :

	Not during the past month	Less than once a week	Once or twice a week	Three or more time a week
Loud Snoring				
Long pauses between Breaths while asleep				
Legs twitching jerking while you sleep				
Episodes of disorientatio confusion during sleep				

5) Other restlessness while you slept (please describe):

APPENDIX E-Lee Fatigue Scale

I am trying to find out about your level of energy during the day. There are 13 items I would like you to respond to. This should take between 1 to 5 minutes of your time.

Instructions: for each of the items listed below, circle the number to indicate how you are feeling

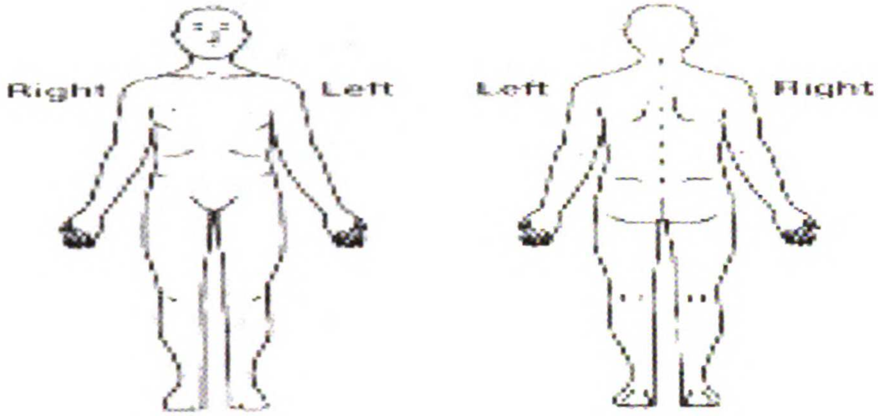
NOW PLEASE COMPLETE THE FOLLOWING ITEMS.

Not at all tired	0	1	2	3	4	5	6	7	8	9	10	Extremely tired
Not at all sleepy	0	1	2	3	4	5	6	7	8	9	10	Extremely sleepy
Not at all drowsy	0	1	2	3	4	5	6	7	8	9	10	Extremely drowsy
Not at all energetic	0	1	2	3	4	5	6	7	8	9	10	Extremely energetic
Not at all active	0	1	2	3	4	5	6	7	8	9	10	Extremely active
Not at all vigorous	0	1	2	3	4	5	6	7	8	9	10	Extremely vigorous
Not at all exhausted	0	1	2	3	4	5	6	7	8	9	10	Extremely exhausted
Keeping my eyes open is no effort at all	0	1	2	3	4	5	6	7	8	9	10	Keeping my eyes open is a tremendous chore
Moving my body is not effort at all	0	1	2	3	4	5	6	7	8	9	10	Moving my body is a tremendous chore
Concentrating is no Effort at all	0	1	2	3	4	5	6	7	8	9	10	Concentrating is no effort at all
Carrying on a conversation is not effort at all	0	1	2	3	4	5	6	7	8	9	10	Carrying on a conversation is no effort at all
I have absolutely no desire to close my eyes	0	1	2	3	4	5	6	7	8	9	10	I have absolutely no desire to close my eyes
I have absolutely no desire to lie down	0	1	2	3	4	5	6	7	8	9	10	I have absolutely no desire to lie down

APPENDIX F- Brief Pain Inventory (Short Form)

1) Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains, and toothaches). Have you had pain other than these everyday kinds of pain today? 1. yes 2. no

2) On the diagram, shade in the areas where you feel pain. Put an X on the area that hurts the most.



3) Please rate your pain by circling the one number that best describes your pain at its **WORST** in the past 24 hours.

0 1 2 3 4 5 6 7 8 9 10

No Pain Pain as bad as

4) Please rate your pain by circling the one number that best describes your pain at its **LEAST** in the past 24 hours.

0 1 2 3 4 5 6 7 8 9 10

No Pain Pain as bad as

5) Please rate your pain by circling the one number that best describes your pain on the **AVERAGE**.

0 1 2 3 4 5 6 7 8 9 10

No Pain Pain as bad as

6) Please rate your pain by circling the one number that tells how much pain you have **RIGHT NOW**.

0 1 2 3 4 5 6 7 8 9 10

No Pain Pain as bad as

7) What treatments or medications are you receiving for your pain?

____

8) In the past 24 hours, how much **RELIEF** have pain treatments or medications provided? Please circle the one percentage that most shows how much.

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

9) Circle the one number that describes how, during the past 24 hours, **PAIN HAS INTERFERED** with your:

A. General Activity:

0 1 2 3 4 5 6 7 8 9 10

Does not interfere interferes

B. Mood

0 1 2 3 4 5 6 7 8 9 10

Does not interfere interferes

C. Walking ability

0 1 2 3 4 5 6 7 8 9 10

Does not interfere interferes

D. Normal work (includes both work outside the home and housework)

0 1 2 3 4 5 6 7 8 9 10

Does not interfere interferes

E. Relations with other people

0 1 2 3 4 5 6 7 8 9 10

Does not interfere — interferes

F. Sleep

0 1 2 3 4 5 6 7 8 9 10

Does not interfere — interferes

G. Enjoyment of life

0 1 2 3 4 5 6 7 8 9 10

Does not interfere — interferes

APPENDIX G-CES-D SCALE

0-Rarely (less than 1 day) 1-Some (1 - 2 days)
2- Moderate (3 - 4 days) 3-Most (5 - 7 days)

1.	I was bothered by things that usually don't bother me.	0	1	2	3
2.	I did not feel like eating; my appetite was poor.	0	1	2	3
3.	I felt like I could not shake off the blues even with help from my family or friends.	0	1	2	3
4.	I felt that I was just as good as other people.	0	1	2	3
5.	I had trouble keeping my mind on what I was doing.	0	1	2	3
6.	I felt depressed.	0	1	2	3
7.	I felt that everything I did was an effort.	0	1	2	3
8.	I felt hopeful about the future.	0	1	2	3
9.	I thought my life had been a failure.	0	1	2	3
10	I felt fearful.	0	1	2	3
11	My sleep was restless.	0	1	2	3
12	I was happy.	0	1	2	3
13	I talked less than usual.	0	1	2	3
14	I felt lonely.	0	1	2	3
15	People are unfriendly.	0	1	2	3
16	I enjoyed life.	0	1	2	3
17	I had crying spells.	0	1	2	3
18	I felt sad.	0	1	2	3
19	I felt that people dislike me.	0	1	2	3
20	I could not "get going."	0	1	2	3

APPENDIX H

Quality of life-CA2

Directions: Below are questions about your well-being. Please mark each line by circling the appropriate number. Put a circle around the number that best represents how you feel today. At each end of the line are extreme opposite feelings. You circle the number that best represents your feelings at present.

1. How is your present state of health?

Extremely poor health **Excellent health**

0 1 2 3 4 5 6 7 8 9 10

2. How easy or difficult is it to adjust to your disease and treatment?

Not at all easy to adjust **Very easy to adjust**

0 1 2 3 4 5 6 7 8 9 10

3. How much enjoyment are you getting out of life?

No enjoyment **A great deal of enjoyment**

0 1 2 3 4 5 6 7 8 9 10

4. Do you feel financially secure?

Not at all secure **Extremely secure**

0 1 2 3 4 5 6 7 8 9 10

5. If you have pain, how distressing is it?

Not at all distressing **Extremely distressing**

0 1 2 3 4 5 6 7 8 9 10

6. How useful do you feel?

Not at all useful **Extremely useful**

0 1 2 3 4 5 6 7 8 9 10

7. How much happiness do you feel?

Not at all happy **Extremely happy**

0 1 2 3 4 5 6 7 8 9 10

8. How satisfying is your life?

Not at all satisfying **Extremely satisfying**

0 1 2 3 4 5 6 7 8 9 10

9. Do you receive enough love from your family and friends?

Not enough or too much love **Just the right amount of love**

0 1 2 3 4 5 6 7 8 9 10

10. Is your disease or treatment interfering with your personal relationships?

Not at all **Completely interferes**

0 1 2 3 4 5 6 7 8 9 10

11. Are you worried (fearful or anxious) about the outcome of your disease?

Not at all worried **Always worried**

0 1 2 3 4 5 6 7 8 9 10

12. How much are you able to do the things you like to do, such as watch TV, read, garden, listen to music, take walks, play tennis, play cards, etc.?

Not at all able **Completely able**

0 1 2 3 4 5 6 7 8 9 10

13. How is your present ability to concentrate on things?

Extremely poor concentration **Excellent concentration**

0 1 2 3 4 5 6 7 8 9 10

14. How much strength do you have?

No strength **A great deal of strength**

0 1 2 3 4 5 6 7 8 9 10

15. Do you tire easily?

I do not tire easily **I tire very easily**

0 1 2 3 4 5 6 7 8 9 10

16. Do you sleep enough to meet your needs?

I do not get enough sleep **I get the right amount of sleep**

0 1 2 3 4 5 6 7 8 9 10

17. How good is your quality of life?

Extremely poor quality of life **Excellent quality of life**

0 1 2 3 4 5 6 7 8 9 10

18. Are you able to take care of your personal needs?

I can't do anything myself **I can do everything myself**

0 1 2 3 4 5 6 7 8 9 10

19. How much pain do you have?

No pain at all **A great deal of pain**

0 1 2 3 4 5 6 7 8 9 10

20. How much appetite do you have?

No appetite at all **Excellent appetite**

0 1 2 3 4 5 6 7 8 9 10

21. How are your bowel movements?

The worst I've ever had (either too much diarrhea or too constipated) **Very good bowel movement (regular pattern, no diarrhea or constipation**

0 1 2 3 4 5 6 7 8 9 10

22. Do you eat enough to meet your needs?

Don't eat right (eat too little or too much) **Eat the right amount**

0 1 2 3 4 5 6 7 8 9 10

23. Are you worried about your weight.?

Not at all **Very worried**

0 1 2 3 4 5 6 7 8 9 10

24. Do you have nausea?

Never **Constantly nauseated**

0 1 2 3 4 5 6 7 8 9 10

25. Do you vomit?

Never **Vomit all the time**

0 1 2 3 4 5 6 7 8 9 10

26. Does food taste different?

Food tastes just fine **Food tastes very different**

0 1 2 3 4 5 6 7 8 9 10

27. Are you able to get around the way you want (walk around your room or home, get out of the house, go shopping, drive your car, or take public transportation, etc.)?

Unable to get around **Can get around on my own**

0 1 2 3 4 5 6 7 8 9 10

28. How satisfied are you with your appearance?

Completely dissatisfied **Completely satisfied**

0 1 2 3 4 5 6 7 8 9 10

29. Are you worried about unfinished business?

Not at all worried **Extremely worried**

0 1 2 3 4 5 6 7 8 9 10

30. Do you feel you are fulfilling your responsibilities to others (family, community, church, etc.)?

Not fulfilling responsibilities **Fulfilling responsibilities**

0 1 2 3 4 5 6 7 8 9 10

31. Does life have meaning for you?

Life has no meaning **Life has a great deal of meaning**

0 1 2 3 4 5 6 7 8 9 10

32. Do you receive enough emotional support?

Not enough emotional support **Just the right amount of emotional support**

0 1 2 3 4 5 6 7 8 9 10

33. Do you feel you make others happy?

I make others very unhappy **I make others very happy**

0 1 2 3 4 5 6 7 8 9 10