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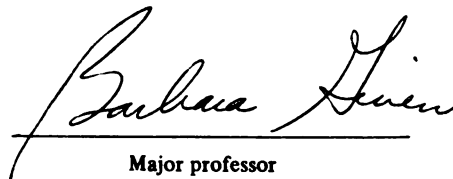
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Characteristics and Process of Care
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**THE RELATIONSHIP BETWEEN FATIGUE IN THE CAREGIVER
OF THE CANCER PATIENT AND CAREGIVER
CHARACTERISTICS AND PROCESS OF CARE**

By

Susan Lynne Jensen

A THESIS

**Submitted to
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ABSTRACT

THE RELATIONSHIP BETWEEN FATIGUE IN THE CAREGIVER OF THE CANCER PATIENT AND CAREGIVER CHARACTERISTICS AND PROCESS OF CARE

By

Susan Lynne Jensen

The purpose of this study is to investigate and describe the experience to fatigue in the caregiver of the cancer patient in relation to the characteristics of the caregiver: caregiver age and employment status, and in relationship to the process of caregiving: number of hours of care reported, the duration of caregiving, and the impact of caregiving upon the caregiver's schedule.

A sample of 248 caregivers of cancer patients participating in the Family Homecare Study were surveyed by means of the Piper Self-Report Fatigue Scale, a visual analogue scale, regarding fatigue experienced related to the caregiving roles. The results were analyzed using the Pearson Product Moment Correlation technique to determine potential relationships. There was a positive, significant relationship between the number of hours of daily care reported and experienced fatigue, and between impact on caregiver's schedule and fatigue. A relationship was also found between fatigue and caregiver age and employment status when using the Ways to Combat Fatigue Scale, a subscale of the total fatigue scale.

Caregiver fatigue and fatigue in general is a concept that needs much more research. Furthermore, the nursing profession needs to develop appropriate interventions for those persons presenting with the complaint of fatigue. Only with

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a more thorough understanding of the concept of fatigue and appropriate treatment methods will the nursing profession be able to most effectively treat those persons presenting with this complaint.

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CHAPTER I

Introduction

Tremendous change has occurred in the delivery of health care over the past few years. Continued change is inevitable for several reasons including the ever changing dictates of the insurance industry, advanced modern technology, increased life span and the trend for family members to care for individuals with chronic disease in the home setting. Overall, at least 3.5 million Americans are chronically ill or disabled and need medical or support services for an extended period of time (Lopez, 1988).

A caregiver, as defined by Hirst and Metcalf (1986), is "one who attempts to meet the physiological and psychosocial needs of the individual" (p. 24). Depending upon the nature of the family member's illness, caregiving can be a twenty four hour a day job. Caregiving demands can be defined as "difficulties or challenges with respect to providing at home care to a family member. Caregiving demands are proposed to have four dimensions: physical care, psychosocial concerns role alterations, and financial alterations" (Stetz, 1987, p. 260).

The four dimensions of caregiving increase the fatigue experienced by the caregiver (Stetz, 1987). The Stetz study (1987) of caregiving demands during advanced cancer found that male caregivers experienced greater difficulty in managing the household, while female caregivers experienced greater difficulty with observing their ill mate experience physical symptoms.

The prevalence of cancer in the population makes it one of the major health problems in this country. The probability at birth of developing cancer before the

age of seventy-five is approximately twenty percent in both men and women, indicative of a high level of morbidity in the population (Hinds, 1985). Cancer is estimated to affect approximately two out of three American families (Hinds, 1985; Vess, Moreland & Schwebel, 1985).

The diagnosis of cancer creates a profound psychological disturbance in most, if not all, people. Emotional distress is, in part, an understandable and realistic response since, notwithstanding advances in treatment, cancer may still entail grave consequences for the individual and family. Nevertheless, public attitudes toward cancer are such that the diagnosis induces in many persons a foreboding greater than that of other diseases carrying equally serious or worse prognoses (Greer & Silberfarb, 1982; Lewis, 1983; Vinokur, Threatt, Caplan & Zimmerman, 1989).

As the disease process of the patient progresses, the caregiver learns to give the necessary emotional, physical and psychological care needed to support his/her family member. The health care professional must learn to adequately support both the patient and the caregiver. Much still needs to be learned about how the functional aspects of caregiving not only influence but also are influenced by the physical and psychological states of the caregiver.

Because the four dimensions of caregiving may add tension to the family dynamics and alter family lifestyle (Stetz, 1987), caregivers often admit to experiencing overwhelming fatigue (Goldstein, Regnery & Wellin, 1981). The added responsibilities inherent in the process of caregiving add to the caregiver's fatigue. Fatigue, a universal experience, may be one of the most prevalent feelings reported in both physical and mental conditions of the human body. This feeling precedes and accompanies most pathological conditions, but it is also

reported to varying degrees in the well population (Piper, Lindsey & Dodd, 1987). Despite this, the concept of fatigue is neither clearly defined nor well understood.

In order to measure fatigue, one must first arrive at an appropriate definition of the concept and determine which of its aspects will be measured. Fatigue can be acute, the result of recent work performance, or chronic, caused by a complex interplay of both somatic and psychological factors (Potempa, Lopez & Reid, 1986). Various authors have provided descriptions of fatigue taken from pathology, physiology and psychology. "Pathology views fatigue as an indicator of neuromuscular or metabolic disorders. Physiological fatigue is a decrease in physical performance. Psychological fatigue affects the whole organism, including mental and physical aspects" (Varrichio, 1985, p. 122). Fatigue is sometimes used synonymously with feelings of anxiety, uncertainty, nervousness, tension and depletion. While these factors may be components, fatigue describes a "feeling of inability to mobilize the energy to carry on . . . is associated with feelings of depression, helplessness, hopelessness, and apathy" (Morris, 1982, p. 266). Piper (1985), a leading nurse researcher in the area of fatigue, developed a working definition of fatigue. "Fatigue, from a nursing perspective, is defined as a subjective feeling of tiredness that is influenced by circadian rhythm. It can vary in pleasantness, intensity and duration. When acute, it serves a protective function; when it becomes unusual, excessive or constant (chronic), it no longer serves this function and may lead to aversion to activity with the desire to escape" (p. 12).

Until recently, health care providers have sought methods to relieve fatigue of patients only, however, the experiences of caregivers of both terminal and chronically ill patients have begun to be researched (Given, Collins & Given, 1988; Hinds, 1985; Stetz, 1987). Fatigue is an often reported feeling in the

caregiver population (Ekberg, Griffin & Foxall, 1986; Goldstein et al., 1981; Goodman, 1986). Chronic fatigue is often attributed to the strain of psychosocial concerns, financial concerns, role alterations and added physical care inherent in caregiving (Goldstein et al., 1981). The strain of caregiving and the increased tension often evident in family dynamics are both forerunners of and concomitant with fatigue (Mitchell, 1986; Morris, 1982). The resultant fatigue inherent in the four dimensions of caregiving, is handled uniquely by each individual family member. Caregiving activities often add excessive or intolerable pressures to the caregiver and thus result in increased caregiving demands (Stetz, 1987).

Statement of the Problem

Understanding the magnitude of the problems facing those persons undergoing treatment for cancer and their caregivers is imperative for today's health care providers. Fatigue of both the caregiver and the patient is an often reported symptom in much of the cancer literature. Because fatigue is a subjective feeling, it has been hard to define, and therefore hard to measure and accurately manage and treat (Piper, 1985).

Certain characteristics of the caregiver may have an influence on the fatigue experience. These caregiver characteristics include, but are not limited to, the sex of the caregiver, the age of the caregiver, the number of roles in which the caregiver functions, whether the caregiver is employed, and if employed, whether this employment is full time or part time. For the purpose of this thesis, the caregiver characteristics to be considered are the age of the caregiver, and the employment status of the caregiver.

The process of caregiving may also have an impact on the fatigue experience (Hinds, 1985; Stetz, 1987; Goldstein et al., 1981). The aspects of the

caregiving process to be considered in this thesis are: the average number of hours of care reported each day, the duration of the caregiving experience, and the impact of caregiving upon the caregiver's schedule.

The problem addressed in this study is to examine the relationship between the experience of fatigue reported by the caregiver of the cancer patient and the hours of care, the duration of caregiving, the impact on schedule, age and employment status of the caregiver. By utilizing the information gained, the health care professional might be able to understand how to better support the caregiver.

Purpose

The purpose of this study is to investigate and describe the experience of fatigue in the caregiver of the cancer patient in relation to the characteristics of the caregiver: caregiver age and employment status, and in relation to the process of caregiving: number of hours of care reported, the duration of caregiving, and the impact of caregiving upon the caregiver's schedule. By increasing our understanding of the experience of fatigue upon the caregiver, the health care professional will have an increased understanding of how to better support the caregiver and assist him/her with the added responsibilities of caregiving.

Research Questions

The research questions for this study are as follows:

- 1) Is there a relationship between reported fatigue and age in the caregiver of the cancer patient?
- 2) Is there a relationship between reported fatigue and employment status in the caregiver of the cancer patient?

- 3) Is there a relationship between reported fatigue and average number of hours of daily care in the caregiver of the cancer patient?
- 4) Is there a relationship between reported fatigue and duration of the caregiving experience in the caregiver of the cancer patient?
- 5) Is there a relationship between reported fatigue and the impact upon the caregiver's schedule in the caregiver of the cancer patient?

Definitions of Concepts

The concepts defined are fatigue, cancer patient, caregiver, the characteristics of caregiver, and the process of caregiving.

Fatigue. Fatigue, from a nursing perspective, is defined as a subjective feeling of tiredness that is influenced by circadian rhythm. It can vary in intensity and duration. When acute, it serves as a protective function; when it becomes unusual, excessive or constant (chronic) it no longer serves this function and may lead to aversion to activity with the desire to escape (Piper, 1987).

Cancer Patient. Those individuals diagnosed with cancer, over the age of eighteen, who are currently undergoing some form of treatment such as radiation therapy, or chemotherapy for either new or recurrent disease, and currently are being cared for in the home.

Caregiver. An individual family member who reports providing physical, emotional, psychological and spiritual assistance and support for the cancer patient in the home setting.

Characteristics of Caregiver. Attributes inherent in each caregiver which may or may not influence caregiving role performance. Those characteristics to be considered in this thesis are age and employment status of the caregiver.

Process of Caregiving. An ongoing method by which the caregiver provides the physical, emotional, psychological, and spiritual assistance and support to the patient as necessary. The aspects of the process of caregiving to be considered in this thesis are the average number of hours of care reported each day, the duration of the caregiving experience, and the impact upon the caregiver's schedule.

Assumptions of the Study

The assumptions for this study are as follows:

- 1) The caregivers' answers to the questions asked reflect their true feelings.
- 2) The subjective feelings of fatigue can be measured by means of an analogue scale.
- 3) Fatigue in caregivers exists and the intensity of fatigue varies from time to time.
- 4) Stress leads to fatigue.

Limitations of the Study

The limitations of this study are as follows:

- 1) Caregivers who agree to participate in this study may be different from those who refuse participation. Therefore, research findings may not be representative of all caregivers of cancer patients.

- 2) The fatigue scale may be difficult to understand and use for some caregivers, especially those with low literacy levels.
- 3) There may be intervening variables that are not controlled for and will not be measured in this study.
- 4) The validity, both construct and content, of Piper's Self-Report Fatigue Scale has not been established for the caregiver population.
- 5) Piper's Self-Report Fatigue Scale was developed and tested in cancer patients and has not been tested on the well population or in the caregiver population.
- 6) The subjective feelings of fatigue are measured at one point in time and may not be reflective of true feelings of caregivers over time or at other points in time.
- 7) The caregivers were not instructed as to any specific time to fill out the fatigue questionnaire, therefore, some may have filled it out in early AM, while others may have filled it out at the end of a long, tiring day, thereby giving misleading results.

Overview of the Study

The study is presented in six chapters. The first chapter introduces the problem, need for the study, purpose for the study, statement of the problem, research questions, definition of the concepts, limitations and assumptions of this study. In Chapter II, the conceptual framework and the concepts of fatigue and caregiving of cancer patients are described. The relationship of these concepts to nursing theory is discussed. A review of the literature is presented in Chapter III. The method, data collection procedure, instruments utilized, reliability and validity, data analysis and interpretation, source of subjects and human rights are

presented in Chapter IV. The presentation of the data analysis is presented in Chapter V, and in Chapter VI, the results of the study are discussed.

CHAPTER II

Conceptual Framework

The purpose of this chapter is to present the conceptual framework upon which the research was based. A brief discussion of the concepts of cancer, caregiving, and caregiver fatigue is included. The relationship of these concepts to Imogene King's nursing framework is then presented, accompanied by the model for the current study.

The diagnosis of cancer has a major impact upon the entire family (Hinds, 1985; Oberst & Scott, 1988; Oberst & James, 1985). Families play an important role in assessing the needs and providing the home care necessary for the cancer patient at home. The ability of family members to assume the additional responsibilities for patient care at home varies as do the ill member's manifestation of needs. The family's ability to adapt to its role as caregiver depends upon the resources available within the family unit and within the larger social support system (Hinds, 1985).

After the initial shock and disbelief of the cancer diagnosis, how a patient and his caregiver view and deal with the disease may be dependent upon the mental health status of the both persons (Northouse, 1984). The distress sometimes witnessed by health care providers in the caregiver and the cancer patient has numerous causes. Cancer can be life threatening; its course in each person is different and uncertain. The disease process often causes both physical and emotional discomforts, and, as a chronic illness, may require long term treatment.

This long term treatment poses numerous adaptive tasks for patients and families, and may drastically change current family lifestyles.

Fatigue is a frequently reported symptom in both the cancer patient and the caregiver. Fatigue in the patient, is, in part, physiologically induced, by both the disease process and the treatment regimen (Haylock & Hart, 1979; Mitchell, 1986). However, fatigue can also be induced in both the patient and the caregiver by the apprehension relation to the diagnosis, treatment regimen, and the resultant change in family dynamics (Morris, 1982). The body's physiological responses relating to this apprehension lead to an increase in the amount of fatigue experienced because of the body's increased energy expenditure (Selye, 1976). Therefore, fatigue in the caregiver can be physically induced by the physical demands of the caregiving experience, and psychologically induced by apprehension regarding the diagnosis, treatment, and prognosis of the cancer patient.

The fatigue described by the population of caregivers of cancer patients needs to be explored so that the health care providers can more effectively support both the patient and caregiver by alleviating and managing the fatigue. If caregiver fatigue is dependent upon such factors as the age of the caregiver, the number of hours of caregiving, employment status, duration of the caregiving status, or the impact of caregiving upon the caregiver's schedule, then the health care provider would initiate appropriate nursing interventions to best alleviate the reported fatigue, thus supporting the caregiver.

The purpose of this study is to investigate and describe the experience of fatigue in the caregiver of a cancer patient in relation to the characteristics of caregiving, such as age and employment status, and the process of caregiving, such as the number of hours of daily caregiving reported, the duration of caregiving,

and the impact of caregiving upon the caregiver's schedule. This can be explored by the following questions: Is there a relationship between reported fatigue and age in the caregiver of cancer patient? Is there a relationship between reported fatigue and employment status in the caregiver of the cancer patient? Is there a relationship between reported fatigue and average number of hours of daily care in the caregiver of the cancer patient? Is there a relationship between reported fatigue and duration of the caregiving experience? Is there a relationship between reported fatigue and the impact upon the caregiver's schedule in the caregiver of the cancer patient?

The conceptual framework for this study is based on the concepts of caregiver fatigue, and caring for cancer patients, and includes a discussion of the relationship between caregiver fatigue to the subconcepts of characteristics of the caregiver: age and employment status of the caregiver, and to the process of caregiving: number of hours of daily caregiving, the duration of caregiving, and the impact of caregiving upon the caregiver's schedule. These concepts are discussed in relationship to King's framework for nursing.

The framework for this study is based on King's view of open systems and King's model of human interaction. King's model has been modified to show the interaction between the nurse, patient and the caregiver. A discussion of King's framework and integration with the problem under study will ensue.

Nursing Framework

The focus of nursing in King's model is based on the concept of human interaction. The model incorporates the idea that the goal of nursing is a concern for the health of individuals, groups, and society. The domain of nursing, according to King (1981), "includes promotion of health, maintenance and

restoration of health, care of the sick and injured, and care of the dying" (p. 4). To coordinate the plan for delivery of health care services, the nurse collaborates with the physician, the family, the patient and other members of the health care team. The nurse's role, after collaboration with the appropriate health care professionals, is to assist both the caregiver and the patient to set mutually agreed upon goals to alleviate the fatigue experienced by both members of the dyad, and assist both the caregiver and the patient to implement appropriate interventions to decrease the fatigue experienced by both the caregiver and the patient. After the implementation of the appropriate nursing interventions to decrease fatigue, the nurse's role is to evaluate the outcomes of applied nursing process in light of the mutual goals set by the patient and the caregiver.

Nursing science is focused on the elaboration of relationships between the clients (in this case - patient and caregiver) and the environment in relation to health (King, 1981). Imogene King's Framework of Goal Attainment is part of what she calls a conceptual framework for nursing. Meleis (1985) states "the theory deals with the central questions of interaction between nurses and clients. King considered questions related to the nature of the process of interaction that lead to the achievement of goals and the significance of mutual goal setting in achieving nursing care goals" (p. 231). Since King's framework focuses on the patient, it must be adapted here to include the caregiver as a legitimate client of nursing. The framework, based upon five explicit and two implicit assumptions, addresses the rationality of human beings and proceeds to develop concepts which are consistently related to clients who can perceive, interpret data, and problem solve.

Implicit in King's framework is the assumption that clients want to participate actively in their care, and are cognitively able to participate. Explicit

assumptions are: clients are social, rational, action and time oriented beings; clients have the right to obtain information and to participate in decisions that may influence their lives and health; the health care providers have the responsibility to inform clients adequately so the clients are able to make informed decisions; persons have the right to either accept or reject any aspect of health care (King, 1981).

King views human beings as open systems interacting with the environment, with boundaries that are permeable to an exchange of matter, energy and information. Included in the conceptual framework are three dynamic, interacting systems: the personal system, the interpersonal system, and the social system.

The personal system is represented by the individual. In Figure 1, the nurse, the patient and caregiver, three personal systems, are illustrated as individuals by enclosing each in a separate circle. The dotted lines indicate that the individual is able to receive or share information. Included in each personal system are characteristics that each individual brings to the situation. The characteristics that the caregiver brings to the caregiving situation are varied, and most will not be measured. However, two characteristics that will be considered in this thesis are the age of the caregiver, and the employment status of the caregiver, since either or both of these characteristics may influence the fatigue that the caregiver experiences.

According to King, an interpersonal system is formed when two individual systems interact. The process of interaction between two or more persons represents a combination of both nonverbal and verbal behaviors that are utilized to reach the desired goal. Inherent in the interpersonal system of the caregiver and the nurse is a consideration of the processes of caregiving. These processes of

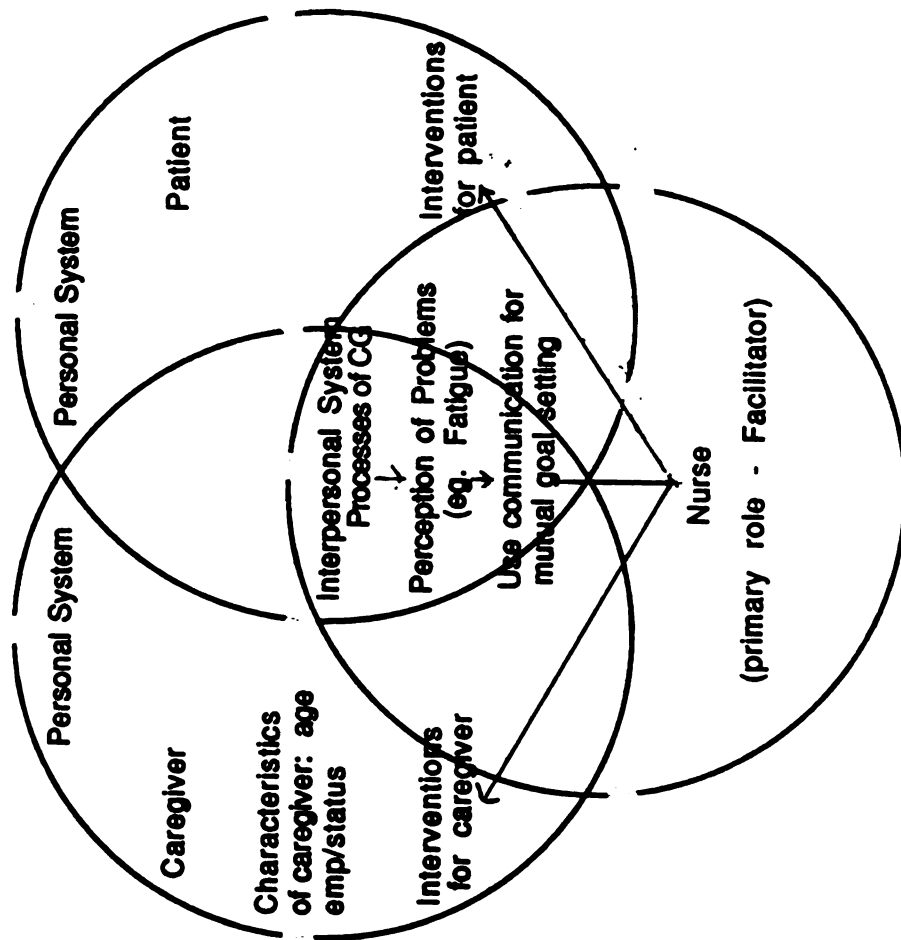


Figure 1. King's Model

caregiving are represented in this study by: the duration of caregiving, the total number of hours of caregiving reported, and the impact upon the caregiver's schedule. The nurse's goal in this situation is for the caregiver to share or communicate his/her feelings and understanding with the nurse regarding the current caregiving situation and the cancer diagnosis, treatment, and prognosis of the patient. Any specific problems that the caregiver experiences such as fatigue, are discussed in related to the characteristics and processes of caregiving. The nurse then assesses the situation and, with the caregiver and patient, assists the dyad to set goals or strategies to effectively deal with the fatigue problem.

The third system is the social system. Social systems are formed when groups who share common interests and goals interact within the society. These systems can include the family, the health care system, support groups, and work systems which can influence people at various times in their life.

The environment, according to King, is also conceptualized as an open system with permeable boundaries which permit an exchange of matter, energy and information with human beings. The nurse needs to assess the environment and act as a facilitator to suggest alterations conducive to promoting health and healthy ways of living. King (1981) states, "the internal environment of human beings transforms energy to enable them to adjust to continuous external environment changes" (p. 5). Any external environmental considerations are beyond the scope of this study.

King also observes that the person continuously adjusts to strain in the internal and external environments, and that these environments are the source of more tension. King (1981) asserts, "satisfaction in the performance of daily living depends upon harmony and balance in each person's environment" (pp. 4-5). The external environment for the caregiver and the cancer patient may be the hospital,

physician's office, or home setting. The patient and caregiver must utilize their own internal environment to cope with the diagnosis of cancer, and possibly the initiation of treatment.

Once the initial treatment for the disease has been concluded, the patient and caregiver no longer have the health care providers readily available to assist their internal resources to cope with the external tensions (decreased ability for the activities of daily living), and their internal tensions (distress, fatigue); therefore, the patient and caregiver must rely on whatever they have learned from the nurse and other health care providers to help them once again achieve harmony and balance in their environment. Additional sources of support include social support systems such as friends, extended family, church and community agencies.

King (1981) defined health as "dynamic life experiences of a human being which implies continuous adjustment to stressors in the internal and external environment through optimum use of one's resources to achieve maximum potential for daily living" (p. 5). Illness, according to King, is defined as "a deviation from normal, that is, an imbalance in the person's biological structure or in his psychological make-up, or a conflict in a person's social relationships" (p. 5). Therefore, both the cancer patient and caregiver are experiencing a deviation from normal, or an imbalance in their psychological make-up, and, according to King, are in a state of illness. The cancer patient is further experiencing an imbalance in the biological structure during the treatment and recovery period. The ultimate goal of both the patient and caregiver is for the patient to return to a state of good health through either a cure or a remission.

King (1981) asserts, "the goals of nursing is to help individuals maintain their health so they can function in their roles" (pp. 4-5). She defines nursing as "A process of human interactions between the nurse and client (in this case, the

caregiver) where-by each perceives the other and the situation; and through communication, they set goals, explore means, and agree on means to achieve goals" (p. 144). The nurse, then, acts as a facilitator, or one who encourages, supports and coordinates in this interaction (see Figure I).

There are six essential variables to be considered in each nursing situation, which must be explored before successful facilitation by the nurse can take place. These variables are described in the context of the caregiver situation and with the caregiver as the client:

- 1) Geographical place of the transacting system (primary care setting or home)
- 2) Perceptions of the nurse and client (caregiver)
- 3) Communication of the nurse and client
- 4) Expectations of the nurse and client
- 5) Mutual goals of the nurse and client
- 6) Nurse and client as a system of interdependent roles in a nursing situation (Fitzpatrick & Whall, 1983, p. 227).

King (1981) defines perception as "a process of organizing, interpreting, and transforming information from sense data and memory; a process of human transactions with the environment; gives meaning to one's image of reality, and influences one's behavior" (p. 24). Therefore, the perceptions of both the nurse and caregiver need to be explored by the nurse before goal setting could begin.

Communication is, according to King (1981), "the structure of significant signs and symbols that brings order and meaning to human interaction" (p. 62). The communication between the caregiver, patient and the nurse must be clear and concise, and based upon adequate perceptions of the nurse and both members of the dyad. Some universal characteristics of communication are nonverbal, verbal,

irreversible, situational, perceptual, and transactional. Fitzpatrick and Whall (1983) state "All human activities that link person to person to environment are forms of communication" (p. 233). "Whereas communication is the transfer of information between two or more individuals, transaction is the transfer of value between two or more persons. Both kinds of interaction are necessary" (p. 223).

According to King's framework, the nursing process is the method by which the nurse assists the client toward the mutually decided upon goals. The nurse, then, acts as a facilitator in King's goal attainment framework. The nurse achieves his/her goals utilizing the dynamic process of human interaction. The perception of the nurse leads to judgments and to actions or nursing interventions by the nurse. At the same time, perceptions of the client lead to judgments and then to actions by the client. The process of human interaction is therefore, a continuous, dynamic process instead of separate incidences in which the actions of one person influences the perceptions and actions of another. The nursing process that therefore must be utilized must also be a continuous, dynamic process, not just the normal cycle of assessment, planning, intervention and evaluation (Fawcett, 1984).

The cancer patient and his/her caregiver would be experiencing many internal and external tensions. The characteristics of the caregiver: age and employment status, and the process of caregiving: duration of caregiving, average hours of daily care reported and the impact upon the caregiver's schedule may impact the fatigue experienced by the caregiver. Through sharing of information between the caregiver, patient and the nurse, and purposeful communication regarding the recommended treatment regimen, the potential internal and external tensions, the potential for pain, fatigue, and other unpleasant side effects in the patient, the recommended procedures to prevent potential complications, the

expectations of both members of the dyad and the nurse are discussed, and various mutual strategies are decided upon. These strategies may be different for the caregiver and the patient and may include attending specific coping groups, the utilization of relaxation techniques, or the initiation of a diet and exercise regimen. Specific strategies the nurse may suggest to alleviate caregiver fatigue may include frequent rest periods, caregiver support groups, proper diet and adequate hydration; or may include a discussion of reducing the number of hours of outside employment or a discussion of how to reduce the impact on caregiver schedule that the process of caregiving currently implies.

Once the patient and caregiver are independent from the nurse, they must continue with these strategies until the goals have been met or are no longer necessary, as the patient is approaching a more optimum state of health. If the patient condition worsens, the nurse may once again re-enter the situation and employ other strategies as deemed necessary by the situation facing the dyad. Since the strategies were mutually agreed upon, both the caregiver and the patient are much more likely to adhere to the recommended regimen, and recovery, or at least a decrease in fatigue experienced, may be achieved at a faster rate.

To summarize, King's theory of open systems and her model of human interaction provide the framework for this study. Figure I is a modification of King's human interaction to show the interaction between nurse and the caregiver and the patient.

In this chapter, a discussion of the concepts of fatigue and caregiving of cancer patients was presented. These concepts were discussed in relationship to King's open systems framework and her model of human interaction. In Chapter III, a review of the literature will be presented.

CHAPTER III

In Chapter III, a review of the literature for the concepts of fatigue and caregiving are presented. The research questions posed in this study are concerned with describing the relationship between both the characteristics of the caregiver: age and employment status, the process of caregiving: average number of daily hours of caregiving, duration of caregiving, impact upon caregiver's schedule, and the experience of fatigue reported by caregivers of cancer patients.

First, the construct of fatigue will be discussed, then the research into the concept of fatigue will be presented. Next, literature discussing the relationship between fatigue and caregiving will be presented, followed by a discussion of the concept of caregiving. Thus, the reader will have a clearer understanding of the concepts of fatigue, caregiving, and their relationship.

Fatigue

Fatigue is believed to be the most prevalent symptom of both physical and mental illness, and is often the first indication of the occurrence of some abnormal process (Hargreaves, 1977; Mitchell, 1986; Morrison, 1980).

In medical terms, fatigue is not a distinct entity, but refers to "a group of phenomena associated with impairment or loss of efficiency or skill, and the development of anxiety, frustration or boredom" (McFarland, 1971, p. 1). McFarland differentiated acute fatigue from chronic fatigue. According to McFarland, the kind of fatigue caused by hard muscular work is called acute, and

results in a temporary loss of efficiency that can be relieved by rest. Chronic fatigue, however, is not relieved by rest or sleep, and is cumulative in its effects. This type of fatigue is mostly a psychological or psychiatric problem characterized by boredom, loss of initiative and progressive anxiety. Fatigue has also been related to selected mood alterations such as depression and anxiety, though any consideration of this relationship is beyond the scope of this study (Potempa et al., 1986).

Despite the universality of fatigue in illness, the lack of clarification of the concept of fatigue may have contributed to its elusiveness as a human phenomenon, and to health care providers' inability to operationalize it with any precision in the clinical setting. The ambiguity surrounding the concept of fatigue is compounded by the large number of definitions attributed to the concept.

Industrial researchers, Yoshitake (1971) and Kashiwagi (1971) have defined fatigue in relation to work. Yoshitake defined fatigue as "such types of unpleasantness as aversion to work, desire for rest, impatience, and physical, mental and neuro-sensory feelings of incongruity, or a feeling of overall unpleasantness" (p. 175). Kashiwagi (1971) defined fatigue as "weakened activation, weakened motivation and physical disintegration" (p. 17).

For health care providers, fatigue needs to be adequately defined so that appropriate measurement and interventions can be initiated for those persons presenting with this complaint. In an attempt to expand upon earlier definitions of fatigue, health care researchers have developed differing definitions that encompass added dimensions of the fatigue concept. Varricchio (1985), a nurse researcher, defined fatigue as "a subjective sense of weariness or tiredness resulting from exertion or stress or as a condition of impaired efficiency resulting from prolonged mental and/or physical activity, or from an attitude of boredom or

from disgust from monotonous work" (p. 122). Fatigue may be the result of an imbalance caused by physiological, psychological or pathophysiological strain.

Another nurse researcher, Mitchell (1986), defined fatigue as an abnormal rate of exhaustion following activity, physical, mental or emotional. Mitchell states that chronic fatigue is most often attributed to tension, can affect few or many body systems, and has manifestations similar to those of sleep deprivation; while generalized fatigue is thought to be the result of midbrain dysfunction.

Piper (1985), a leading nurse researcher instrumental in developing a unifying framework for the conceptualization of fatigue, states that nursing theory related to fatigue can be generally accepted as reflecting the domain of nursing: health, the individual, nursing, and environment. Piper's definition of fatigue is reflective of each of these domains and is defined as "a subjective feeling of tiredness that is influenced by circadian rhythm. It can vary in pleasantness, intensity, and duration. When acute, it serves a protective function; when it becomes unusual, excessive, or constant (chronic), it no longer serves this function and may lead to the aversion of activity with the desire to escape" (p. 12). Piper's definition will be utilized for this study because this definition encompasses the domain of nursing: health, the individual, nursing and the environment.

Piper's framework states that there is a relationship between fatigue and the four domains of nursing: health, the individual, nursing, and the environment. She asserts that various psychological, biochemical, and psychosocial mechanisms are likely to produce or influence fatigue symptoms in cancer patients. In the caregiver, chronic fatigue is often attributed to both physical and psychological aspects inherent in caring for those family members who are ill with cancer.

Fatigue Research

There is a dearth of research into the concept of fatigue, possibly because of the ambiguity of the concept and the difficulty health care professionals have had in adequately defining and measuring fatigue. The Pearson-Byers Fatigue Feeling Checklist has been used by Haylock and Hart (1979) on a population of cancer patients to measure fatigue, and Japanese researchers Kashiwagi (1971) and Yoshitake (1971) developed their own checklists for use in measuring fatigue in the well population. However, these instruments have no reported reliability and validity and have not been tested in the caregiver population.

Piper et al. (1987, 1988) have done much work developing a conceptual framework from which to study the experience of fatigue. This proposed framework permits multidisciplinary perspectives, and identifies strategies for developing nursing theory related to fatigue in the population of cancer patients. Piper (1985) states that a variety of strategies may be utilized to develop nursing theory regarding the concept of fatigue. For the development of Piper's conceptual framework of fatigue in cancer patients, a deductive approach based on a literature review from five disciplines most active in researching the concept of fatigue (nursing, medicine, psychology, physiology and ergonomics) was used.

In Piper's framework (1989), both the subjective (perceptual) and the objective (behavioral, biochemical and physiological) indicators of fatigue are discussed (Appendix A). Piper asserts that because most of the research in fatigue has used healthy populations, findings from these studies may not be applicable to cancer patients.

The remainder of the fatigue framework discusses fatigue mechanisms. Though the exact mechanisms that cause fatigue are unknown, the patterns most often reported to influence fatigue in both healthy and ill populations are:

activity/rest patterns, sleep/wake patterns, disease patterns, treatment patterns, environmental patterns, symptom patterns, psychological patterns, changes in regulation/transmission patterns, social patterns, life event patterns, innate host factors, accumulation of metabolites, and changes in energy and energy substrate patterns.

Piper (1988) asserts that each one of these mechanisms that influence fatigue in both the well and ill population needs to be investigated more thoroughly in order for the health care provider to better care for the individual with cancer, and give the necessary emotional and physical support to the caregiver.

Piper, Lindsey and Dodd (1984) developed a visual analogue fatigue scale by which to measure subjective dimensions of fatigue. Piper (1988) tested the fatigue scale on 50 newly diagnosed breast and lung cancer patients and reported that the fatigue scale effectively measured the temporal, affective, intensity/severity and sensory dimensions of fatigue. The reliability of the scale, tested using Cronbach's Alpha as a measure of internal consistency, was reported to be .82. No figures were reported for the validity of this instrument.

Though there are no studies focusing on fatigue in the caregiver population, two other nurse researchers, Haylock and Hart (1979) and Rhoten (1982) conducted research focusing on the symptomatology and manifestations of fatigue in the ill population.

Haylock and Hart (1979), focusing upon the symptomatology of fatigue, studied fatigue levels and fatigue symptoms of thirty cancer patients undergoing radiation therapy by utilizing the Pearson Byers Fatigue Feeling Checklist. This checklist defined the fatigue feeling continuum in ten short easily understood phrases: extremely peppy, very lively, very refreshed, quite refreshed, somewhat

refreshed, slightly pooped, fairly well pooped, petered out, extremely tired, and ready to drop. These two researchers found that in this population of cancer patients, the fatigue symptoms which had statistically significant relationships with fatigue levels lends further support to the notion of a physical, rather than psychological etiology of this phenomenon. A limitation of this study is a rather small sample of thirty.

Rhoten (1982) conducted a study investigating the relationship between subjective and objective fatigue levels in the post-surgical patient, using a convenience sample of five patients, twenty-five years or older, who were admitted to the hospital for abdominal surgery. Rhoten found that fatigue was not a primary concern for post-surgical patients, that their main concern was pain, the discomforts of intravenous catheters, and nasogastric tubes. Major limitations to Rhoten's study are her extremely small sample size, the fact that no reliability or validity was reported for her instruments, and the fact that she didn't specifically state which methods she used for her qualitative data analysis, severely limiting the generalizability of this study to a larger population.

In summary, research into the concept of fatigue, is still in the preliminary stage. Piper is currently developing a nursing framework from which to operationalize her definition of fatigue. Though the applicability of this framework is being investigated using the Piper Fatigue Self-Report Scale on a population of cancer patients, the health care professional eventually may be able to expand the framework to include those caregivers of cancer patients and other well individuals who are experiencing fatigue.

Other researchers, such as Haylock and Hart (1979) and Rhoten (1982), have also investigated fatigue in ill individuals and found that fatigue appears to have a physical rather than psychological etiology. The applicability of these

findings to the caregiver of the cancer patient is not known, however, because fatigue in the ill individual may manifest itself differently than fatigue in the well individual. Because of an obvious lack of adequate research into the concept of fatigue, more investigation is necessary before health care providers can adequately provide care for persons with this complaint.

Caregiving and Fatigue

The following studies discuss the relationship between caregiving and fatigue. The caregiving concerns expressed by these studies show how the demands of caregiving can lead to increased fatigue in the caregiver. There are no studies that examine the relationship between fatigue and caregiving in the caregiver of the cancer patient.

Goldstein, Regnery and Wellin (1981) reported on the relationship between caregiving and fatigue in a population of long term patients. Interviews and observations in the homes of a randomized sample of 60 long term patients of non specified disease processes, supplemented by visits to about 30 others, confirmed that for the majority of caregivers, the most difficult problem is fatigue. They concluded that the time, place, energy demands and expectations of caregiving and those of other roles the caregiver may have are sometimes not easily reconciled with each other, causing increasing conflict and tension in the caregiver, and eventually increasing fatigue levels. This fatigue is due, in part to the increasing demands of caregiving, and, in part, to the difficulty the individual may have resolving the conflicting roles that now exist for the caregiver.

Stetz (1987) conducted a descriptive study to explore the demands put on spouse caregivers of the terminally ill adult cancer patient (N = 65). A one time, semi-structured at home interview was conducted. These interviews revealed nine

major categories of caregiving demands. The demand reported most frequently was managing physical care, including treatment regimen, and imposed changes in lifestyle (69% of sample). The next two most frequently reported caregiving demand categories (39%) were managing the household and finances, and standing by in case the patient needed assistance. The other six categories included alterations in spouse and caregivers' well-being and pattern of living, constant vigilance, unmet expectations from the health care system, the cancer itself, anticipating the future, and alterations in relationship with spouse. These categories make up the four dimensions of caregiving.

Research findings by Oberst and James (1985) and Oberst and Scott (1988) on the adjustment of the couple after cancer surgery suggest that, though the intensity of distress experienced by patients and spouses was similar, concerns of spouses change over time. Spousal concerns related to the physical health of the ill family member were replaced by worries over their own health thirty days after the spouse was discharged from the hospital. From this study, one might argue that caregivers of cancer patients experience worries about both the family members' health as well as their own health, perhaps increasing the severity of fatigue experienced.

Hinds (1985), studied 83 families who care for patients with cancer at home to determine the resources utilized and to assess how families coped with caregiving, and met the needs expressed by the patients. Hinds found that 27% of the families said that they needed guidance to assist them with physical care, 13% of the families reported requiring financial assistance, and 53% identified several areas which indicated their caregiving role was overwhelmed with psychological strains which were difficult, if not impossible to resolve. Hinds found that families seldom sought assistance for social or emotional needs. Although 23% of

the families knew about the community services available, only 8% used them. The other major concern expressed by the family caregivers was the difficulty in obtaining information; in particular, the difficulty obtaining concrete answers from physicians, getting information by telephone, or finding out about daily progress or set backs from the nurses. Evident from this study is the potential for increasing caregiver fatigue, because of the increased strain inherent in the caregiving role.

In summary, because of the scarcity of adequate research into the caregiving role, and specifically into the relationship between fatigue and caregiving in the population caring for cancer patients, further research clarification and elaboration of adaptation to the role of caregiver during various stages of a terminal illness such as cancer is needed.

Goldstein, Regnery and Wellin (1981) found that a relationship existed between caregivers of long term patients and fatigue to the increased energy demands of caregiving and the difficulty of reconciling other previously existing roles to the caregiver role. Stetz (1987) researched caregiver demands and found that 69% of the caregivers reported providing physical care, though in this study these demands were not directly related to fatigue in the caregiver. Oberst and James (1985) and Oberst and Scott (1988) researched the emotional and physical adjustment of the patient and caregiver returning home after cancer surgery and found that caregiver concerns change over time, with an increase in concern for the caregiver's own physical and emotional well-being replacing the original concern for the patient. Hinds (1985) found that 27% of cancer caregiver families (N = 83) needed help with physical care, and 53% of these families needed assistance with psychosocial or emotional concerns related to caregiving.

Though the majority of these studies do not report a direct relationship between caregiving concerns and fatigue, this author contends that these concerns do indeed lead to increased fatigue in the caregiver of the cancer patient. The role conflict often inherent in the caregiving role leads to distress, which over a long period of time, may lead to increased fatigue levels in the caregiver. More research is needed to establish this relationship more clearly, enabling the health care professional to better plan appropriate interventions to assist the caregiver.

Caregiving

The concept of family caregiving is receiving increasing amounts of attention from researchers as well as health care providers (Bowers, 1987; Hinds, 1985). Throughout history, caregiving has been a function of the family. Then, as now, how well families were able to cope with the added responsibilities of caregiving depended upon the resources and coping skills of the various family members (Hinds, 1985). Though caregiving might be difficult, it was and is, considered a family responsibility and may be done out of love and commitment. Stetz (1987) defined caregiving as "providing physical, emotional, psychological and spiritual assistance and support for the ill individual in the home setting" (p. 260). Because Stetz's definition most holistically describes the caregiving role, it will be used in this thesis, though the spiritual dimension of caregiving will not be discussed.

The characteristics of the caregiver may impact the actual caregiving and eventually may result in an increase in fatigue experienced (Goldstein et al., 1981). The characteristics of the caregiver to be considered in this thesis are age and employment status of the caregiver. Goldstein, Regnery and Wellin (1981) state "the better the caretaker's health, and the more available the assistance of

others, the less arduous is the caretaker's role, as well as the less disruptive of his or her other roles and involvements" (p. 26). Conversely, the more physically taxing the caregiving role is, the greater is the likelihood that virtually all other roles and activities will be sacrificed to the demands of caregiving. The researchers assert that if a caregiver has multiple other obligations such as occupational, the caregiving demands and expectations of the role may not be easily reconciled with each other and caregiver fatigue is the result.

Though no literature was found discussing the relationship between age of the caregiver and caregiver fatigue, it is logical to assume that as the caregiver grows older, and physical health declines, the fatigue experienced increases. The characteristics of the caregiver, age and employment status, are very important for the health care provider to consider when determining which interventions to employ to best support the caregiver.

The process of caregiving is also important to consider when attempting to determine the appropriate interventions to alleviate caregiver fatigue. Duration of the caregiving experience, the number of hours of daily caregiving reported, and the impact of caregiving upon the caregiver's schedule are all aspects of the process of caregiving to be considered.

Bowers (1987), in a discussion of the caregiving process, outlined five conceptually distinct, overlapping categories of intergenerational caregiving. Only one of these categories includes what is generally considered to be caregiving, the hands on caregiving behaviors. The remaining categories include anticipatory, preventive, supervisory, and protective care. Although all of these categories may not be applicable to the population of caregivers of individuals with cancer, nevertheless, in each category are components of care that caregivers of this

population must remit in order to grapple with caregiving demands, possibly causing a resultant increase in fatigue.

Two components of the process of caregiving to be considered in this thesis are number of hours of care and duration of caregiving. To more thoroughly understand the relationship between these two components of the process of caregiving and the concept of fatigue as it relates to work done, an investigation into the history of research of the fatigue is necessary.

In the period surrounding World War I, extensive research was carried out in England to measure productivity in the munitions industry (Cameron, 1973). The researchers concluded that the output of the worker was limited in some manner by fatigue, and that by the alleviation of fatigue, production could be maintained at a higher level. This work, though primitive by today's standards, laid the groundwork for the more sophisticated research that was to follow in fatigue.

The second major wave of interest in fatigue occurred during the 1940s and 1950s, with the focus of interest on military aviation. The work of Bartlett (1943) clearly established the pattern of breakdown in skilled performance which occurs in fatigue, and also under the influence of other types of stressful conditions. The occurrence of this fatigue, also known as battle fatigue, demonstrated that pilots can only work a limited number of hours and after that limit has been reached, the pilots' judgment, capabilities, and the speed with which they made the judgments became impaired. The findings of this war-time research was extended to the commercial airlines in 1946, immediately after the end of World War II, and are still in effect today.

Two more recent major researchers in the area of industrial fatigue are Kashiwagi (1971) and Yoshitake (1971). Kashiwagi (1971) developed a thirty

item fatigue rating scale given to engine drivers of the Japanese National Railway (N = 65) to enable the researcher to judge human fatigue through a person's appearance. This fatigue scale was purported to have three dimensions: weakened activation, weakened motivation and physical disintegration. These dimensions were found to be common to almost all kinds of work (Kashiwagi, 1971).

Yoshitake (1971) studied the association between the frequency of symptoms of fatigue and the feeling of fatigue on bank personnel in Tokyo (N = 387) by utilizing a 20 item checklist to measure three dimensions of fatigue: General Feeling of Incongruity in the Body, Mental Symptoms, and Specific Feelings of Incongruity in the Body. Yoshitake found that the correlation between the frequency of symptoms (average of each dimension), and the feeling of fatigue was extremely high. He hypothesized that the results indicate the more numerous the symptoms, the greater the feeling of fatigue, because the number of complaints of symptoms are considered to be the most dominant factor for expressing the feeling of fatigue.

Because both Kashiwagi (1971) and Yoshitake (1971) developed and tested their instruments on a population of healthy Japanese workers, the question must be raised about how transferable the results of this research is to the American cancer caregiver population. The reliability and validity of these instruments are not reported. Also, there are cultural differences between Americans and Japanese which may influence the validity of these instruments. Therefore, though both instruments may be appropriate for measuring fatigue in the American cancer caregiver population, no study has reported the use of either instrument in this population.

To summarize, fatigue in the workplace has been examined by the Industrial Health Research Board (1914) in England, by Bartlett (1943), and more

recently by Japanese researchers, Kashiwagi (1971) and Yoshitake (1971). From past research, we know that by decreasing fatigue, a resultant increase in productivity is expected (Cameron, 1973). Bartlett (1943) found that as the number of hours of work increased, a resultant decrease in pilot's judgment was noted. Yoshitake (1971) noted that the more symptoms of fatigue that were reported, the greater the feeling of fatigue.

Therefore, based on the work of Bartlett, Kashiwagi and Yoshitake, an assertion can be made that as caregivers care for their family members over time, and as the number of hours of daily caregiving increase, an increase in the fatigue experienced by this population would be reported. Caregiving is work, and work, according to the industrial researchers, leads to fatigue. These studies also point out that other dimensions of caregiving besides the physical dimension leads to fatigue (Kashiwagi, 1971; Yoshitake, 1971) but that these dimensions are difficult to isolate and adequately measure.

Much still needs to be learned about caregiving in general, and about caregiving in the cancer patient specifically. The process of caregiving encompasses different aspects to each individual caregiver. While the physical act of caregiving and the number of hours of caregiving may induce fatigue, most family caregivers experience sometimes overwhelming psychosocial and financial concerns, as well as major role alterations, including impact upon schedule. Caregiving for a family member may last days to months, or even years, thereby prolonging the strain and fatigue as well as the uncertainty accompanying the disease process for both the patient and the caregiver. The findings of the various studies of caregiving indicate that the health care professional must learn better ways to communicate to the patient and caregiver, and to support the dyad by providing both physical, spiritual, emotional, and psychosocial assistance to the

family. If this can be accomplished, then fatigue in both the patient and caregiver could be decreased, and a more positive caregiving experience would be the result of the health provider's actions.

Summary

Fatigue and caregiving have been considered in this chapter. Fatigue is an ambiguous concept, difficult for the health care provider to understand, define and measure in the general population and specifically in the population of caregivers. Piper's instrument for measuring fatigue is relevant because it is a reliable measure of fatigue, which has been tested in a population of cancer patients.

Caregiving, on the other hand, is a concrete role, though it has different dimensions as mentioned by Stetz. Only recently has this concept received increased attention and research. The cause and effect of fatigue upon the caregiver must be understood in order for the health care provider to more effectively support both the patient and the caregiver. By increasing our understanding of the various causes of fatigue, and its effects upon the caregiver of the cancer patient, health care professionals may be able to increase the quality of care to both cancer patients and their caregivers, increase the health and well-being of the caregiver, more adequately meet the patient and the caregiver's needs, decrease institutionalization of the patient, and decrease possible abuse, both physical and substance in both the patient and the caregiver.

Chapter III has presented a review of the concepts of fatigue and caregiving. Chapter IV will present the methodology and procedures utilized in this research study.

CHAPTER IV

In Chapter IV, the methodology and procedures utilized in this research study are presented. The sample, settings, data collection procedure with human rights protection, the instruments, scoring techniques and procedures for data analysis are discussed. The purpose of the study is to examine and describe the experience of fatigue in the caregiver of the cancer patient in relation to caregiver age and employment status, and to the number of hours of caregiving reported, the duration of caregiving and to the impact upon the caregiver's schedule. The research hypotheses are presented as an introduction to a discussion of the methodology.

Hypothesis 1: Older caregivers experience more fatigue than younger caregivers.

Hypothesis 2: Caregivers who are employed outside the home experience more fatigue than those caregivers not employed outside the home.

Hypothesis 3: The greater the number of hours of daily caregiving reported, the greater the fatigue experienced by the caregiver.

Hypothesis 4: The longer the duration of caregiving, the greater the fatigue experienced.

Hypothesis 5: There is a relationship between the fatigue experienced by the caregiver and the impact upon schedule reported.

This study utilized data gathered from the larger, one year longitudinal study entitled The Family Homecare Center Study funded by the National Center

for Nursing Research #1 RO1 NR1915, B. A. Given, principal investigator. The purpose of the Family Homecare Cancer Study, was to follow solid tumor cancer patients and their family caregivers in order to describe the needs for, the receipt of, and the outcomes of care provided by families and other home care and community agencies located in community based settings.

The research attempts to measure patients' need for care as evidenced by their symptoms, fatigue, physical and mental health, and functional health status, and to measure caregivers' responses to those needs through caregiver level of involvement in that care, their perceived burden associated with providing care, and their mental health status and utilization of services as part of their own health care needs (Given, 1987).

The population of caregivers of cancer patients was drawn from those persons being treated in both small and large community based medical care settings in Michigan, affiliated with the Michigan State University College of Human Medicine. The nursing staff at each site was instructed in the necessary procedures to follow to identify potential participants, and to explain the study to those potential participants. The study was explained to the patient and caregiver, with instructions given to the caregiver to mail back the card to Michigan State University or call the nursing research office if interested in participating in the study. Those that mailed back the cards or contacted the researchers by telephone were contacted by health care researchers and asked appropriate screening questions to determine if the potential participants met the selection criteria. Those patients and caregivers who met criteria were assigned to data collectors who had been oriented to correct interviewing techniques. Questionnaires were administered in telephone interviews by health care researchers to those caregivers who met eligibility requirements and had been entered into the study. Self-

administered booklets, along with consent forms, were then sent to those caregivers who had completed the Wave 1 telephone interviews, to finish and mail back in the self-addressed stamped envelope provided to the participants. After the intake interview, the caregivers were contacted at three month intervals for follow-up questionnaires for a period of one year.

Sample

The study participants consisted of a sample of 248 caregivers drawn from the larger population of 303 caregivers of cancer patients completing Wave 1 of the Family Homecare Cancer Study.

The following were the criteria for selection of caregivers for this study:

- 1) Subjects were selected from a population of caregivers of non-institutionalized patients diagnosed with cancer and living within the state of Michigan.
- 2) Participants must be caring for a person diagnosed with solid tumor cancer or lymphoma.
- 3) Participants must be caring for a person currently undergoing treatment for new or recurrent disease, experiencing symptoms or a decreasing level of activities of daily living.
- 4) Participants must be caring for persons between 20 to 70 years of age.
- 5) Both the caregiver and the patient consented to being in the study.
- 6) Participants must answer at least 10 out of 17 questions on the Piper Fatigue Self-Report Scale.

Because the sample was self-selected and not the result of random selection, the results of this study should not be considered to be representative of all caregivers of cancer patients.

Data Collection Procedures

The data for this thesis were taken from selected questions from Wave 1 of the caregiver's telephone interview and self-administered booklet, and thus only cross-sectional relationships among the variables will be considered.

Each data collector contacted his/her assigned caregiver at Wave 1 to administer a telephone questionnaire to gather sociodemographic information such as age, employment status, duration of caregiving and the number of hours of daily caregiving. After this information was gathered, the data collector mailed the caregiver the self-administered booklet which included among other measures the adapted Piper Fatigue Self-Report Scale and the Impact On Schedule Scale. The caregiver was instructed to fill out this self-administered booklet completely and mail it back to Michigan State University. If the self-administered booklet was not returned in three weeks, a telephone call was made to the caregiver to remind him/her and to answer any questions that the caregiver may have regarding the questionnaire. Results from both the telephone interview and the self-administered booklet were then compiled and entered into the computer for analysis.

Operational Definitions of the Study Variables

Fatigue

In order to describe caregiver perceptions of fatigue, a shortened adaptation (19 items) of Piper's Fatigue Self-Report Scale was used (Appendix B). The first seventeen items from this form directly measure the total experience of

fatigue and were utilized for this research (Appendix C). Categories of responses for each question of the Piper Self-Report Fatigue Scale are listed in Appendix C.

Caregiver's responses to the experience of fatigue were assessed on an analogue scale by the caregiver placing an "x" on a line 21 centimeters long indicating the current amount of fatigue experienced. Data collectors then measured the line from the beginning of the line to where the "x" crosses the line, and recorded this number in centimeters.

Items 1 through 12 directly measure intensity or severity of fatigue, and were considered as a subscale of the total fatigue scale. Items 13 through 17 measure Ways To Combat Fatigue and were considered as a subscale of the total fatigue scale.

Impact On Schedule

The Impact On Schedule Subscale (Given, 1987) was utilized to gauge the impact of caregiving on the caregiver's schedule. The responses to each item are recorded on a five point Likert scale ranging from strongly agree (5) to strongly disagree (1) (Appendix D).

Processes of Caregiving

To evaluate the process of caregiving components of number of hours of daily caregiving and duration of the caregiving experience, questions 31 and 33 in the Involvement Section of Wave 1, telephone interview, of the study were utilized. Question 31 asks "How many hours/day do you provide direct care for your relative?" Question 33 asks "How long have you been providing care for your relative?" Answers for daily caregiving range from 0 - 24 hours, while answers for duration of caregiving was measured in months.

Characteristics of the Caregiver

To evaluate the characteristics of the caregiver, age and employment status of the caregiver, question 5 on the screening form asks: "What is your birthday?", and question one in the Employment section asks "Are you currently employed for pay outside the home?". Age of the caregiver was measured in years.

Employment status was measured by caregiver responses of employed or not employed.

The Instruments

There were two instruments used in this study to measure the variables. Fatigue in the caregiver of the cancer patient was measured by the Piper Fatigue Self-Report Scale. This instrument, shortened for the Family Homecare Cancer Study, is a 19 item visual analogue scale (Appendix C), taken from the original Piper Self-Report Fatigue Scale (Appendix E), developed by Piper, Lindsey and Dodd (1984). The visual analogue scale is, according to Gift (1989), a horizontal or vertical line usually 100 millimeters in length, with or without gradations, utilized by the participant to measure intensity of a particular concept. The shortened, adapted form, utilized for this thesis measures only the total fatigue score, and does not measure any of the fatigue dimensions separately. Seventeen of the nineteen items on the adapted fatigue scale will be utilized for this analysis (Appendix C). There is no reported validity, either construct or content for the shortened form of the fatigue scale. The Cronbach's alpha coefficient for the total fatigue scale (items 1-17) for this study is .89.

To measure impact upon the caregiver's schedule, a subscale of the Caregiver Reaction Scale was utilized (Appendix D). This subscale measures the effect caregiving has upon the caregiver's schedule. The internal consistency for

the Impact On Schedule subscale reported as a Cronbach's alpha of .84 (Given, 1987).

Scoring

The scoring for the fatigue scale and impact upon schedule subscale is as follows. Responses to each question on the Piper Fatigue Self-Report Scale were measured in centimeters from the beginning of the line to where the caregiver marked an "x" on the line. This distance, from 0 to 21 centimeters, was given a numerical score for each of the seventeen items measuring the total fatigue experience of the caregiver. These scores were then summed and averaged, giving a total fatigue score, or scale score, for each caregiver. Scale scores could range from 0 to 21, with 21 representing extreme fatigue.

Total scores for the Impact On Schedule subscale range from 1 to 5. The responses to each item were recorded on a five point Likert scale, ranging from strongly agree (5) to strongly disagree (1). The higher the score, the more impact on the caregiver's schedule caregiving activities exhibit.

Pretest of the Instruments

Although no pilot study was conducted, various members of the research team for the Cancer Family Homecare Study critiqued the instruments and assessed the clarity of instructions and questions. The Piper Fatigue Scale has been piloted in other Piper studies. The Cancer Family Homecare Study was conducted utilizing the format presented in this chapter.

Analysis of the Data

Sociodemographic/economic data and information regarding age, level of education, employment status, income and other background information of the

cancer caregiver were analyzed using descriptive statistics. These variables are described in detail in Chapter V.

The Pearson Product Moment Correlation Coefficients were calculated to test each hypothesis. The score of each of the characteristics of the caregiver considered (age and employment status) was correlated separately to the mean of the total fatigue score. The scale score for the Impact On Schedule Scale was correlated using Pearson Correlation analysis to the mean of the total fatigue score to obtain the relationship between the process of caregiving and the fatigue experienced by the caregiver of the cancer patient. The frequencies, mean and percentages, along with the tables summarizing the frequencies of sociodemographic categories, fatigue and impact upon schedule scores as well as other related factors are presented in Chapter V.

Protection of Human Rights

Specific procedures were followed to assure that the rights of the study participants were not violated. Approval of the human rights protection procedures was granted by the Michigan State University Human Subjects Review Committee December 5, 1989 (Appendix F). Consent for the longitudinal study was obtained by the Family Homecare Cancer Study researchers from each physician involved before approaching oncology patients and their caregivers regarding participation in the study. An explanation of the research study and goals, the approximate time the caregiver and cancer patient would be involved in participation, the nature of the questions to be asked, and assurances of anonymity were provided each participant as part of the letter of explanation. Signed consent forms were required from both patient and caregiver. Number-coded questionnaires were separated from patient and caregiver identifying the date they

were received by the researchers. All the data were transcribed in aggregate form for computer analysis.

Summary

A discussion of the methodology utilized in this study was presented, along with a detailed discussion of the sample, instruments used, human rights protection, procedures, and statistical analysis strategy. In Chapter V, the data which describes the study sample and addresses the research hypotheses are presented.

CHAPTER V

Data Presentation

Overview

The purpose of this study is to examine and describe the experience of fatigue in the caregiver of the cancer patient in relation to the characteristics of the caregiver (caregiver age and employment status), and to the processes of caregiving (number of hours of daily caregiving reported, the duration of caregiving, and the impact of caregiving on the caregiver's schedule).

In this chapter, data which describes the study sample and addresses the research hypotheses are presented. The study sample is described by age, sex, education, employment status and income. Additional descriptive data including the study variables of number of hours of daily caregiving reported, duration of caregiving, and impact on the caregiver's schedule are also presented.

Several statistical analysis techniques were used to analyze the data. Descriptive statistics include frequencies, percentages, means, standard deviations, and ranges. The inferential technique used was the Pearson Product-Moment Correlational analysis to determine the existence of a relationship between fatigue and characteristics of the caregiver and processes of caregiving in the caregiver of the cancer patient. The data are presented as follows: descriptive data pertaining to the sample, descriptive data related to fatigue, reliability data, and descriptive and inferential data pertaining to the research hypotheses.

Descriptive Analysis of Data

Study Sample

The sample consisted of 248 caregivers of cancer patients participating in the larger longitudinal Family Homecare Cancer Study (Grant #R01 NR1915). The study sample was derived from those caregivers completing Wave 1 of the study, which included a self-administered questionnaire and a telephone interview.

Sociodemographic Descriptors

The sociodemographic descriptors used in the present study were age, sex, education, employment status and income. The age of the caregivers ranged from 20 to 81 years with a mean age of 54.8 years and a standard deviation of 12.6 years (see Table 1).

Table 1

Distribution of Caregiver Age

Age	N	Percentage
20-35	21	8.5
36-50	67	27.0
51-60	73	29.3
61-70	65	26.2
71-81	22	9.0
TOTAL	248	100.0

The ages of the patients ranged from 18 to 83 years, with a mean of 59.1 years and a standard deviation of 12.3 years. Seventy percent (N = 174) of the cancer patients were over 50 years of age.

Thirty five percent (N = 85) of the caregivers were male, while 65 percent (N = 163) of the caregivers were female.

Fifty percent of the caregivers (N = 124) reported working either full time or part time, while fifty percent of the caregivers (N = 124) reported being unemployed or retired.

The educational level of the caregivers was distributed over six categories, from a grade school or less education to a graduate level in college or professional degree. Eighty-nine percent (N = 219) reported graduating from high school or higher education (see Table 2).

Table 2

Distribution of Caregiver Education

Education	N	Percentage
Grade school or less	6	2.4
Some high school	23	9.3
High school graduate	91	36.7
Some college	81	32.7
College graduate	24	9.7
Grad/prof degree	23	9.3
TOTAL	248	100.0

Annual non adjusted household income ranged from less than \$5,000 a year to more than \$50,000 per year with a mean of \$29,350 (see Table 3).

Table 3

Distribution of Household Income

Income (in thousands)	N	Percentage
\$ 1,000 - \$ 9,999	12	6.3
\$10,000 - \$24,999	67	34.8
\$25,000 - \$39,999	48	25.0
\$40,000 - \$49,999	22	11.5
\$50,000 plus	43	22.4
	—	—
TOTAL	192	100.0
Missing*	53	

*Missing data may be explained by 535 caregivers who chose not to disclose their household income to the research staff as this was an optional question.

The duration of caregiving in months ranged from one month to 218 months, with a mean of 23.6 months and a median of nine months (see Table 4).

The hours of care that caregivers reported giving daily range from zero to 24 hours, with a mean of 4.3 hours (see Table 5).

Descriptive Data Related to Fatigue Self-Report Scale

The range of the means of the total fatigue score was from 0 to 18.4 with a mean of 8.2 and a standard deviation of 4.2. See Table 6 for frequency distribution of the total fatigue scale.

Table 4

Distribution of Duration of Caregiving in Months

Duration (in months)	N	Percentage
1 - 6	102	41.5
7 - 12	48	19.5
13 - 24	34	13.8
25 - 48	37	15.0
49 - 218	25	10.2
	<hr/>	<hr/>
TOTAL	246	100.0
Missing*	2	

***Missing data may be explained by 2 caregivers who were unable to state how long a duration in months they had been caregiving.**

Table 5

Distribution of Hours of Daily Care

Hours of Care	N	Percentage
< 1	46	19.2
1 - 3	106	44.2
4 - 10	60	25.0
11 - 24	28	11.6
	—	—
TOTAL	240	100.0
Missing*	8	

*Missing data may be explained by eight caregivers that were unable to stage how many hours of daily care they gave to the cancer patient. Possibly, because of the cyclical caregiving necessary for the cancer patient related to treatment methods, if the study had asked how many hours of weekly or monthly caregiving the caregiver had done, then the results might have been different.

Table 6

Distribution of Mean Fatigue Scores for Caregivers

Mean Score	Items 1-17	Items 1-12	Items 13-17
< 1	6	6	7
1.00 - 7.00	95	111	69
7.01 - 11.00	80	63	66
11.01 - 21.00	67	68	106
	—	—	—
TOTAL	248	248	248

The range of the severity subscale (items 1-12) was from zero to 19.1, with a mean of 8.0. The range of the WTCF subscale (items 13-17) was zero to 21, with a mean of 9.6.

The total fatigue score was computed from the mean of items 1-17 on the Piper Fatigue Self-Report Scale (see Appendix C). Table 7 shows the mean, and standard deviation, and the total item correlation for each item in the questionnaire. The range for all questions was from 0-21.

Reliability of the Instruments

The reliability of the instruments was measured by computing coefficient alpha, which is an indication of homogeneity or internal consistency and estimates the extent to which different subparts of an instrument are equivalent in terms of measuring critical attributes (Polit & Hunglar, 1987). The coefficient alpha of the shortened 17 item Piper Fatigue Self-Report Scale was found to be .89, indicating a good reliability. The alpha coefficient of the severity subscale (items 1-12) is .89. The alpha coefficient of the 'Ways to Combat Fatigue (WTCF)' subscale (items 13-17) is .86. The internal consistency reported for the 'impact on schedule' subscale is a Cronbach's alpha coefficient of .84 (Given, 1987).

Presentation of the Data Related to the Research Hypothesis

In this section, descriptive and inferential statistics are presented as related to the individual research hypotheses. The data will first be analyzed using the total fatigue score (items 1-17), then using the severity subscale (items 1-12), and finally using the WFCF subscale (items 13-17).

Hypothesis 1: Older caregivers experience more fatigue than younger caregivers.

Table 7**Means & Standard Deviation for Individual Items of Total Fatigue Scale**

Item #	Mean	Standard Deviation	Total Item Corr.
1	10.0	6.6	.75
2	9.0	6.6	.76
3	11.2	7.9	.62
4	7.2	6.7	.59
5	9.4	6.2	.54
6	7.0	6.2	.73
7	7.7	6.8	.74
8	6.1	5.7	.76
9	10.3	7.0	.58
10	8.6	6.7	.52
11	6.3	6.7	.39
12	4.3	5.5	.30
13	8.3	6.0	.68
14	10.1	6.6	.81
15	11.8	6.8	.71
16	9.9	6.2	.55
17	10.1	7.0	.67

See Table 8 for a comparison of statistical findings for each scale utilized. The analysis for this hypothesis utilizing the total fatigue score was based on the Pearson Product Moment Correlation. The correlation coefficient was $-.03$, indicating a slightly negative correlation existing between caregiver age and the fatigue experienced. However, the $p = .30$, indicates this finding is not significant at the $p < .05$ level of significance therefore, this hypothesis is rejected using the total fatigue scale.

Analyzing this hypothesis utilizing the severity subscale only, the correlation coefficient is $.01$ ($p = .43$). This finding is not significant at the accepted level of significance ($p < .05$), therefore the hypothesis is rejected. Analyzing hypothesis #1 utilizing the WTCF subscale, the Pearson r is $-.13$ with a ($p = .02$), which indicates that this finding is statistically significant at the $p < .05$ level, therefore, the hypothesis is supported when utilizing this scale.

Hypothesis 2: Caregivers who are employed outside the home experience more fatigue than those caregivers not employed outside the home.

The correlation coefficient for hypothesis 2 was $-.01$, indicating again that there is a slightly negative relationship between caregiver fatigue and employment status in the caregiver of the cancer patient. However, this finding is not statistically significant ($p = .42$) at the $p < .05$ level of significance, therefore, the hypothesis is rejected.

Analyzing the question utilizing the severity subscale, the correlation coefficient was $.04$ ($p = .26$), which is not statistically significant. Analyzing this hypothesis using the WTCF subscale, the Pearson $r = -.13$ ($p = .03$). This finding

Table 8

Correlation of Study Variables to Fatigue

	Total Fatigue Scores (1-17) N = 248	Severity Subscale (1-12)	WTCF Subscale (13-17)
Age	-.03 p = .30	.01 p = .43	-.13 p = .02*
Employment	-.01 p = .42	.04 p = .26	-.13 p = .03*
Hours of Care	.09 p = .06	.09 p = .08	.06 p = .16
Duration of Caregiving	.00 p = .48	.03 p = .33	-.06 p = .19
Impact on Schedule	.41 p = .00*	.42 p = .00*	.22 p = .00*

*Indicates statistically significant findings.

is statistically significant, therefore the hypothesis can be accepted when using the WTCF subscale.

Hypothesis 3: The greater the number of hours of daily caregiving reported, the greater the fatigue experienced by caregivers.

The Pearson Correlation Coefficient was used to examine the potential relationship between number of hours of caregiving reported and reported fatigue among the caregivers of cancer patients involved in this study. The Pearson r was .09, indicating a positive relationship between number of hours of care reported by caregivers and the fatigue experienced by this population ($p = .06$). This finding is not statistically significant at the $p < .05$ level, but is approaching significance.

Analyzing this hypothesis using the severity subscale, the correlation coefficient is .09 ($p = .08$). This finding is not statistically significant, and the hypothesis can be rejected. Analyzing this question using the WTCF subscale, the Pearson $r = .06$ ($p = .16$), which is not statistically significant, therefore the hypothesis can be rejected.

Hypothesis 4: The longer the duration of caregiving the greater the fatigue experienced.

The Pearson Correlation Coefficient was used to determine any potential relationship between the duration of caregiving and the fatigue that the caregivers reported. The correlation coefficient for this question was .00, indicating that essentially no relationship exists between the fatigue reported and the duration of care reported by the caregivers of cancer patients ($p = .48$).

Analyzing this hypothesis utilizing the severity subscale, the correlation coefficient is .03 ($p = .33$). Using the WTCF subscale, the Pearson $r = .06$ ($p =$

.19). These findings are not statistically significant. This hypothesis can be rejected using all three scales and subscales.

Hypothesis 5: There is a relationship between the fatigue experienced and the impact upon schedule reported by the caregiver.

Pearson Correlation Coefficients were used to determine if a relationship exists between caregiver fatigue and impact upon schedule experienced by the caregiver. The correlation coefficient for this hypothesis is .41, ($p = .00$) indicating that a positive relationship exists between reported caregiver fatigue and the impact upon schedule that the caregiver reports. Therefore, the hypothesis can be accepted.

Analyzing this hypothesis utilizing the severity subscale, the correlation coefficient was .42 ($p = .00$). Analyzing the question using the WTCF subscale, the Pearson r was .22 ($p = .00$). All three findings are statistically significant at the $p < .05$ level of significance, and therefore the hypothesis is accepted using all three instruments of fatigue.

Discussion

The following section will be a discussion of each one of the findings as these findings appear in the previous section. Sixty-five percent of the caregivers are over the age of 50, while seventy-one percent ($N = 160$) of the cancer patients are over the age of 50. The majority of caregivers participating in this study (65%) are female. The educational level of caregivers is fairly evenly distributed with only about 19% at the college graduate or above level and only 2% at the grade school or less level. Also 50% of the caregivers reported being employed, while 50% of the caregivers reported not working. This is probably explained by

considering that the majority of the population is over 50 years old, and may be retired or close to retirement age. Twenty-two percent of the respondents have an annual household income of at least \$50,000, while six percent reported income under \$10,000. Therefore, 72% of the participants' yearly income ranged between \$10,000 and \$50,000. The duration of caregiving ranged from one month to 216 months with a mean caregiving time of twenty four months. The hours of care that the caregivers reported ranged between 0 to 24 with mean of 4.3 hours of daily care.

The total fatigue score was obtained from the mean of questions 1-17 of the Piper Shortened Fatigue Scale. Ninety-five caregivers (38%) complained of slight fatigue (a mean of 1 to 7 on fatigue scale). Eighty caregivers (32%) complained of moderate fatigue, (a mean of 7.01 to 11.0 on the fatigue scale). Sixty-seven caregivers (28%) complained of experiencing severe fatigue in their caregiving role (a mean of 11.01 to 21.0 on the fatigue scale). The complaints of fatigue by caregivers varies quite widely across this scale (see Table 6).

Discussion of the Data Relating to the Research Hypothesis

Hypothesis 1: No correlation was found between either the total fatigue score and caregiver age, or the fatigue severity subscale and caregiver age. Notice that the majority of caregivers are over the age of 50. Increased caregiver age alone did not indicate or lead to a higher level of fatigue. Perhaps the slightly negative relationship indicates that as caregivers age, there are less conflicting roles for the caregiver to participate in and therefore, the caregiver can fulfill the caregiving role with less fatigue experienced because of less role conflict. No literature was found discussing the relationship between age and fatigue.

A statistically significant inverse relationship was found, however, between caregiver age and the WTCF subscale, perhaps indicating that as the caregiver ages, fewer of the methods that may have been previously utilized to combat fatigue successfully currently are used or work for the caregiver.

Hypothesis 2: No relationship between caregiver severity of fatigue or total fatigue and employment exist in the caregiver of the cancer patient. Perhaps the slightly negative relationship indicated that working caregivers are slightly less fatigued for various reasons, such as working people may be better organized because of the increased number of roles, and getting out of the house provides diversion which may alleviate the fatigue and depression that the caregiver may otherwise feel. Those caregivers still working may have less ill persons at home that they are caring for thereby allowing these caregivers to continue their employment.

A statistically significant inverse relationship was also found to exist between caregiver employment status and the WTCF subscale, indicating that those caregivers who are employed are not able to utilize the different ways to combat fatigue successfully, most likely due to the time constraints that the employment and caregiving roles place upon the caregiver. Goldstein, Regnery and Wellin (1981) concluded that the energy demands and expectations of caregiving and those of other roles that the caregiver may have are sometimes not easily reconciled with each other causing increased tension and conflict in the caregiver.

Hypothesis 3: In this sample of cancer caregivers, a positive nearly significant relationship was found between the number of hours of daily care and both the total fatigue score and the severity of fatigue experienced by this population. Though no study reported on the relationship between fatigue and the

number of hours of caregiving, Bartlett (1943) clearly established the pattern of breakdown in performance which occurs in fatigue related to the number of hours of work.

There was no significant relationship found between numbers of hours of care and WTCF subscale.

Hypothesis 4: No relationship existed between duration of care and either the total fatigue scale or either of the two subscales. The basis for this hypothesis was that caregiving over time takes an emotional toll on the caregiver. The findings from this study are supported by Haylock and Hart (1973) who found a physical rather than psychological basis for fatigue in their population of cancer patients.

Hypothesis 5: There was a positive relationship between the reported total fatigue score, the severity and WTCF subscales and impact upon caregiver schedule. All of these findings are statistically significant at the $p < .05$ level. Therefore, the more that the caregiver's schedule is a burden to the caregiver, the greater the fatigue experienced.

Utilizing the total fatigue score, and the severity subscale, the characteristics of caregiving considered (age and employment status) and the duration of care, did not affect the fatigue experienced by the caregiver of the cancer patient. However, impact on the caregiver schedule did affect the fatigue experienced by the caregivers.

Summary

In Chapter V, data were presented which describe the characteristics of the sample, reliability of the instruments, and analysis of the data with respect to each of the five hypotheses. The Piper Fatigue Self-Report Scale was found to have a

reliability of .89, while the alpha of the 'severity of fatigue' subscale was .89, and the alpha of the 'WTCF' subscale was .86. The 'impact on schedule' subscale reported an alpha of .84 (Given, 1987).

No relationship was found between caregiver fatigue and the characteristics of care: age and employment status, or hours of daily caregiving or duration of care. However, a statistically significant relationship was found between caregiver fatigue and impact on schedule.

In Chapter VI, the summary and conclusions for this thesis will be presented.

CHAPTER VI

Summary, Interpretation, and Implications of Findings

Overview

In Chapter VI, a summary and interpretation of the research findings are discussed. Implications for nursing practice along with recommendations for future research are offered.

Summary of Findings

A sample of 248 caregivers of cancer patients participating in the Family Homecare Center Study were surveyed regarding the fatigue experienced related to their caregiving roles. The concept of fatigue, because it is ambiguous and subjective, has been difficult for the health care professional to define, measure and therefore, to treat in both the patient and in the caregiver population. Fatigue in the patient population more likely has physiological origins, but in the population of caregivers, fatigue may be physically or psychologically induced and therefore, treatment, to be most effective, needs to focus on these causes.

King (1981), a nursing theorist, maintains that the nurse's role in alleviating the fatigue of the caregiver is to encourage open communication between the caregiver, patient and the nurse regarding problems of both the patient and the caregiver. The nurse must be aware of the characteristics of the caregiver such as age and employment status. After the caregiver has communicated whatever problems he/she has, such as fatigue, the nurse must also be aware of the various processes of care such as duration of the caregiving role,

number of hours of daily care given and the impact of caregiving on the caregiver's schedule. Taking both the characteristics of the caregiver and the processes of care into account when considering a problem such as fatigue, the next step is mutual goal setting to alleviate the problem, along with appropriate caregiver education. The nurse, then, is the facilitator in this process.

Though fatigue has been researched by industrial researchers as well as health care researchers, no one definition, or instrument to measure the concept, or best way to treat the complaint has emerged. In fact, there have been no studies researching the fatigue experienced by the caregiver of the cancer patient. However, Piper (1985) has developed a definition of fatigue using a nursing perspective and is in the process of developing and refining a self-report analogue scale as an instrument to measure the concept of fatigue.

In the present research, fatigue was self-reported using a shortened form of the Piper Fatigue Scale at Wave 1 of the Family Homecare Cancer Study by 248 caregivers. The purpose of this study was to investigate and describe the experience of fatigue in the caregiver of the cancer patient in relation to the characteristics of the caregiver: age and employment status, and in relation to the processes of caregiving: the number of hours of daily caregiving, the duration of caregiving and the impact of caregiving upon the caregiver's schedule.

Because the total fatigue scale incorporates two different subscales measuring two different aspects of the concept of fatigue: severity and ways to combat fatigue, and because the total fatigue scale is not as helpful in assessing and planning nursing interventions as the two subscales taken separately, no further discussion of the total fatigue scale will be presented; only the two subscales and their relation to the study variables will be discussed.

After the results were analyzed, the findings revealed that the majority of the caregivers were female, and over the age of 50. No relationship was found between caregiver age and experienced fatigue severity, or between the employment status of the caregiver and fatigue. No relationship was found between duration of caregiving and the severity of fatigue experienced, or between the number of hours of daily care reported and experienced fatigue severity. However, there was a positive, significant relationship between impact on caregiver's schedule and fatigue. There was a significant relationship found between caregiver age, employment status and impact on schedule in relation to the WTCF subscale.

Statement of Conclusions

There was no relationship between experienced fatigue and caregiver age, employment status, the number of hours of daily caregiving or duration of caregiving. There was a relationship between both severity of fatigue and the WTCF scale and impact upon schedule. There was an inverse relationship between both caregiver employment and age in relation to the WTCF subscale.

Discussion of Conclusions

Hypotheses 1, 2, 3, and 4 were not supported. There was no relationship found between the severity of fatigue experienced by the caregiver of the cancer patient and caregiver age, employment status, the number of hours of daily caregiving, or duration of caregiving. There were no studies investigating caregiver age, employment status or duration of caregiving and the possible relationship of these variables to caregiver fatigue, therefore, no statement of similarities or dissimilarities can be made. Even though no relationship was found between fatigue and each of these variables independently, this author contends

that each of these variables should be considered in conjunction with the other variables contained in the characteristics of the caregiver and the processes of care, perhaps yielding increased relationships between these variables and fatigue.

Even though the relationship between the number of hours of daily care and severity of fatigue was not statistically significant, the correlation approached significance. Though no study reported on the relationship between fatigue and number of hours of caregiving, Bartlett (1943) clearly established the pattern of breakdown in performance which occurs in fatigue related to the number of hours of work. Haylock and Hart (1973) found a physical rather than psychological etiology of fatigue existed in the population of cancer patients. Goldstein, Regnery and Wellin (1981) found that in a population of 60 caregivers of long term patients the time, place, energy demands and expectations of caregiving and those of other conflicting roles caused increased tension and fatigue levels. The findings of this research support these studies.

An inverse relationship was found between caregiver age, employment status and the WTCF subscale. This finding would indicate that as caregivers age, either fewer ways to alleviate fatigue are attempted or fewer of these methods are effective for this population. Also, the WTCF scale may not be appropriate for elderly caregivers because of normative changes associated with the aging process, such as a decreased desire and need for sleep. Therefore, the elderly caregiver may not perceive sleep or napping as an appropriate way to alleviate fatigue.

An inverse relationship also was found to exist between caregiver employment status and the WTCF subscale, indicating that possibly because of the role conflict between working outside the home and caregiving, the caregiver is not able to utilize such methods as naps, exercise, distraction and planned rest periods. Goldstein, Regnery and Wellin (1981) discussed the role conflict inherent

in the caregiving role, while Stetz (1987) discussed the caregiving demands on those persons caring for individuals with cancer and concluded that managing physical care and the resultant changes in lifestyle were two of the most difficult demands that caregivers face.

Hypotheses #5 was supported. There was a relationship between caregiver fatigue severity, the WTCF scale and the impact upon the caregiver's schedule. A strong relationship existed between fatigue and impact on schedule. This finding has strong implications for the health care professional because the more the caregiver's schedule is a burden to the caregiver, the greater the fatigue experienced.

Limitations

Interpretation of the findings of this study are offered with caution because of several serious limitations. First, the Piper fatigue scale, utilized to measure fatigue in the caregiver, is a visual analogue scale. Some caregivers have difficulty understanding the directions to this kind of scale and responding accordingly. Only 248 caregivers, out of 303 participants completed the Piper fatigue scale completely enough to be included in this study (completing 10/17 items), and 28 respondents didn't complete the questionnaire at all. The reasons why these twenty-eight caregivers did not complete the self-report fatigue scale are not known. Also, the fatigue scale was difficult to score because some participants marked their "x" above the line, while others marked substantially below the line, possibly decreasing the reliability of the measurements.

In addition, neither the content or construct validity has been established in the caregiver population. The Piper scale was developed and tested in the cancer patient population and has not been tested in any other population. Finally, the

caregivers participating in this study were not instructed as to any specific time to fill out the self-report scale, therefore, some may have filled the scale out in early morning when they were refreshed, while others may have filled it out late in the day when they were more fatigued.

Another limitation of this study is the fact that there may be many other intervening variables such as physical, mental and emotional health of the caregiver, and involvement in other roles that are not controlled for or measured in this study. Also, the variables included in the characteristics and processes of caregiving were considered independently of each other, when perhaps if they were considered together, the results may have been different.

Recommendations

Based upon the findings of this research, several recommendations are advanced. Piper's definition of fatigue is useful because it incorporates the four dimensions of nursing; however, this definition is difficult to quantify and therefore to operationalize, making measurement of the concept more difficult. Therefore, this author proposes an eclectic definition that attempts to make fatigue more understandable:

Fatigue may be acute, normative or chronic . . . a subjective feeling existing at one point in time on a continuum from weariness to complete exhaustion, resulting from physical, mental or emotional activity. Acute fatigue is most often caused by excessive physical or mental exertion and can be relieved by rest. Normative fatigue may be influenced by circadian rhythm and results from the activities of daily living, while chronic fatigue is most often the

result of prolonged stress or tension on the body and is less likely to be relieved by rest alone.

This definition will allow the health care professional to separate the different kinds of fatigue the client may present with and to plan interventions based upon the type of fatigue experienced.

To most effectively meet the needs of caregivers who currently experience fatigue or those who may in the future, the CNS must first understand the predictors of fatigue. These predictors would include the characteristics of the caregivers and the processes of caregiving, but would also include consideration of physical, emotional, mental, social and medical or health demands that the caregiver experiences.

Each of these predictors of fatigue in caregivers must be assessed independently and in conjunction with the others to determine if the potential for fatigue exists. The fatigue experienced by the caregiver may be acute, normative or chronic. Interventions will be determined by the predictors of fatigue and the kind of fatigue the caregiver experiences (see Figure 2).

Further, based upon the findings of this research and King's theory of goal attainment (1981), a slightly different model from that proposed in chapter two is now proposed (Figure 3). Note that the processes of care have been moved to the interpersonal system of the caregiver and patient. Also, note that the personal system of the nurse is smaller than in Figure 1, signifying that though the nurse can have an impact on the caregiver and the patient, other health care professionals also have input. Also, the nurse is involved with the caregiver for just a small portion of the caregiving time, both in and out of the caregiving situation. The CNS must be efficient, effective and empathetic when dealing with the caregiver and the patient.

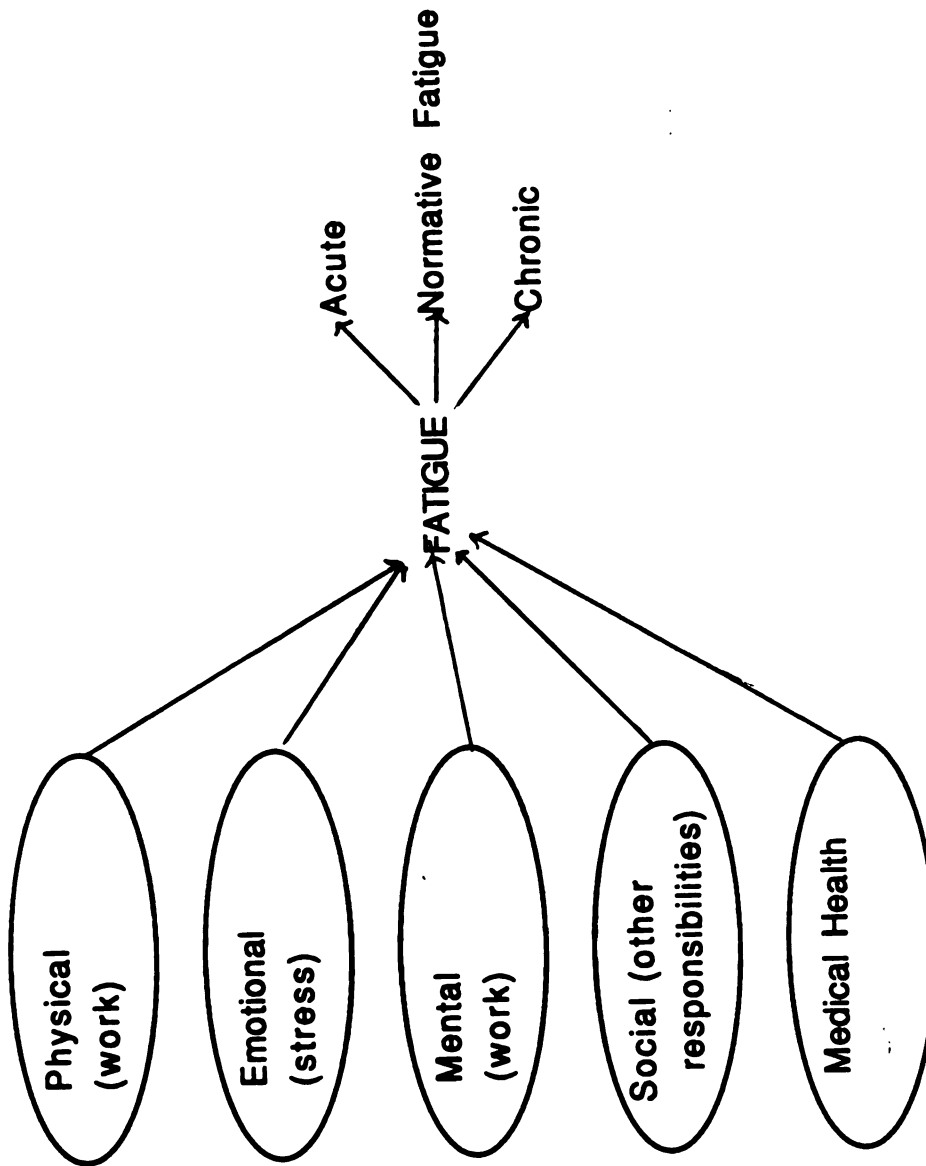


Figure 2. Predictors of Fatigue

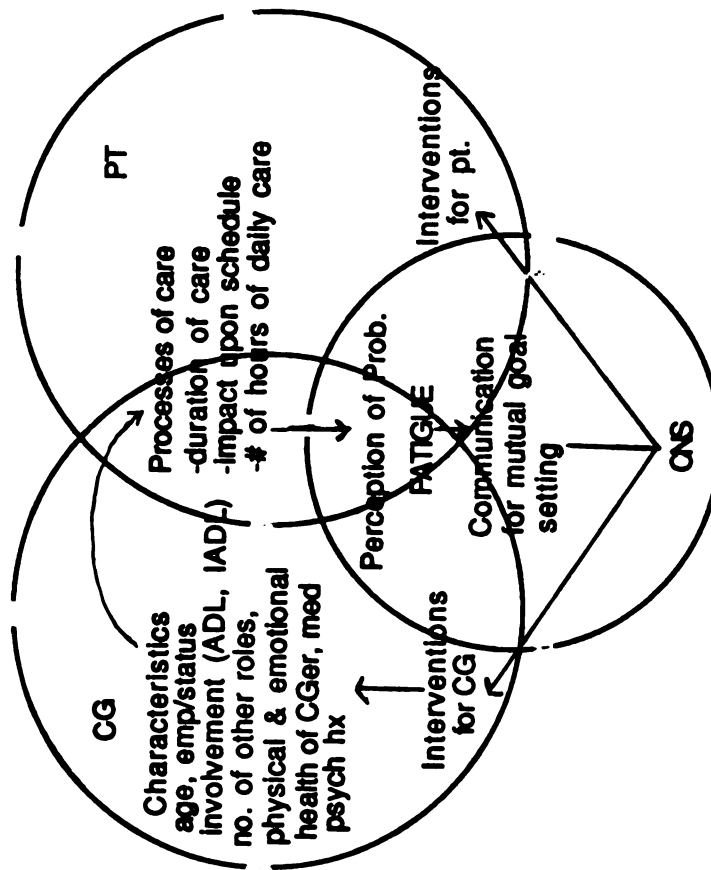


Figure 3. King 's Model - Updated

In addition, evaluation of the interventions is a necessity, along with continued reassessment of portions of the characteristics of the caregiver and the processes of care. Based upon evaluation of the interventions, continued assessment of these predictors of fatigue, and also continued communication between the nurse and the caregiver, new, mutually agreed upon goals and interventions might be advanced. Continued communication and reevaluation is necessary especially if the condition of the patient deteriorates and caregiving demands increase.

A final recommendation concerns the Piper Self-Report Fatigue Scale. Analogue scales are extremely effective for measuring severity of a subjective concept such as fatigue (Gift, 1989). Therefore, items 1 through 12 on Piper's shortened form are valid measures of fatigue. However, this author would further recommend that a 'not applicable' box be added to each question. Many participants didn't answer some of the questions, but did answer others, possibly because certain questions did not apply to them and therefore the participants left them blank giving missing data. By adding the 'not applicable' box, the participants would be able to indicate which questions did not apply to them, thereby giving increasingly meaningful data.

Furthermore, items 13-17, the WTCF subscale does not measure the intensity of the concept but measures instead ways to combat the fatigue experienced. The health care professional should be assessing the caregiver's understanding of the various ways to combat fatigue, perhaps this information could be gleaned by utilizing a Likert five point scale for these or similar questions.

Implications for Nursing Practice

As our population ages and health care costs continue to rise, the number of caregivers of patients living at home with both terminal and chronic illnesses will also continue to rise. The Clinical Nurse Specialist (CNS) will increasingly be dealing with this population who will be presenting with various complaints, some acute and others chronic possibly relating to the caregiving role. As in our population of caregivers, fatigue may be a presenting complaint of some of the caregivers that present to the health care professional in the future. The CNS must identify effective assessment strategies and interventions for prevention of fatigue as well as for restoration in the caregiver population.

In the present research, the conceptual model (Figure 3) is derived from King's (1981) theory of goal attainment. Using King's (1981) theory to guide nursing practice, it is understood that individual beliefs, perceptions, and values are formed prior to entering the interpersonal system with the health care provider. Therefore, it is within this system that the nurse and caregiver develop a common, shared understanding for working toward the mutually set goal.

In the personal system of the caregiver (Figure 3), the CNS must be aware of the various characteristics of the caregiver such as age, employment status, and the number of other, possibly conflicting, roles that the caregiver has. In the present study, neither age nor employment status, considered alone, exhibited a relationship with the severity of caregiver fatigue. However, the CNS must be cognizant of the potential for these variables to adversely affect the caregiver's ability to function in his caregiving role. In the interpersonal system (Figure 3), the CNS must further be aware of the processes of caregiving, such as the number of hours of daily care rendered, the duration of the caregiving experience and the impact of caregiving upon the caregiver's schedule.

Further, the CNS must be cognizant of the potential for fatigue that exists for the new caregiver whenever a newly diagnosed cancer patient presents for treatment. Therefore, interventions to prevent fatigue for the new caregiver will be presented along with potential interventions for existing caregiving fatigue for the caregiver of the cancer patient who present to the CNS both directly as a client or indirectly as caregiver to the client.

When a newly diagnosed cancer patient and his/her caregiver presents to the CNS, this research indicates that fatigue may be a problem. The CNS must have interventions available to prevent or decrease the fatigue that is most likely to occur. Using anticipatory guidance, the CNS should review the disease process and treatment modalities with both the patient and caregiver, along with the changes in the activities of daily living of the patient that may occur. The CNS should explore coping mechanisms in place with the dyad and investigate the stress reduction techniques that the caregiver and patient normally use. If the coping mechanisms and stress reduction techniques are not sufficient, the CNS, along with the patient and caregiver, should decide the appropriate coping and stress reduction techniques to incorporate and assist the dyad with these new behaviors.

Further, the CNS should assist the new caregiver with priority setting with regard to caregiving demands and other social obligations that the caregiver might have. Other aspects of caregiving that the CNS might explore with the caregiver is time management, allocation of resources and the exploration of seeking help from family members, friends and other forms of social support. For example, the CNS might suggest that the caregiver utilize a chore person while the caregiver was at work, or plan a time on the weekend when for a few hours a family member would come to the caregiver's home so that the caregiver could attend church, go out to eat with friends, or do some shopping.

If the caregiver presents to the CNS indirectly, accompanying the patient to the health care professional, the CNS has less time available to intervene with the caregiver. There are still interventions that the caregiver can utilize. However, the assessment of the causes or predictors of fatigue might be more difficult to obtain.

After fatigue has been identified by the caregiver as a problem, the CNS must, with his/her knowledge of both the characteristics of the caregiver and the processes of caregiving, suggest interventions that are both feasible and easily implemented. These interventions need to be presented to the caregiver in a non-threatening way so that the caregiver will choose some, or all, of the strategies in the mutual goal setting procedure that is essential if the interventions are to be successful. Some of the interventions may include strategies included in the WTCF subscale. Though these interventions should be appropriate for the age of the caregiver, potential interventions to be considered include:

1. Encourage caregiver to keep diary of activities that increase perception of fatigue.
2. Encourage daily rest periods of pre-set lengths and pre-determined time.
3. Instruct caregiver in energy saving techniques of daily care (proper body mechanics when lifting, prepare meals sitting on a high stool rather than standing, etc.).
4. Encourage progressive activity, schedule moderate increase in exercise on a daily basis (eg. walking around the block or in a mall with a friend).
5. Determine motivations or hobbies of caregiver for activities.

6. Teach relaxation methods to deal with the stress of caregiving demands.
7. Provide opportunities for allowing caregiver to express concerns regarding the caregiving role.
8. Encourage and provide ancillary personnel to assist the caregiver with the role as determined by the assessment by the CNS as to both the characteristics of the caregiver and the processes of caregiving:
 - a. chore person
 - b. aide or orderly assistance
 - c. LPN or RN
 - d. physician
 - e. Physical therapist or occupational therapist
 - f. psychiatrist or psychologist
 - g. caregiver support groups
9. Encourage medical/CNS evaluation to rule out physiological causes of fatigue.
10. Encourage use of respite services, or a planned time daily for self.

If these interventions have been implemented and fatigue develops or continues, then perhaps if the caregiver is employed and is able to take a leave of absence or retire early, this is a plausible alternative for the CNS to explore with the caregiver. The CNS may be able to explore other roles the caregiver has and determine which ones, if any, the caregiver may be able to surrender at least temporarily, in an attempt to alleviate the experienced fatigue.

If the caregiver presents to the CNS with the complaint of fatigue, then there are various assessment techniques available to determine the causes of caregiver fatigue. Based on the findings of this research, the fatigued caregiver

would also report a greater impact upon his/her schedule. However, to fully understand the causes of the caregiver's fatigue, a thorough assessment is necessary.

First, a thorough history and physical should be conducted to rule out medical problems. Data to be collected includes age, employment status, the number of other roles that the caregiver has, involvement as measured by activities of daily living, nutrition and exercise assessment and significant medical history. To determine how well the caregiver is coping with the increased demands of caregiving, a psychological examination may be utilized. A caregiver evaluation should be done to investigate the components of the characteristics of the caregiver and the processes of care (see Figure 3). Next, a physical assessment should be completed with appropriate laboratory tests to rule out physical causes of fatigue. Finally, the caregiver should be instructed to fill out the severity fatigue scale every day for seven days at the end of the day, and to keep a diary of daily activities for the week.

After one week, the caregiver should bring in the completed fatigue scales and diary. The CNS should then review the findings and results of the examination and laboratory tests with the caregiver. Based upon the needs of the caregiver, the type and causes of fatigue and the results of the history and physical, the CNS can determine appropriate interventions and with the caregiver, mutually set goals for the caregiver to utilize to alleviate fatigue. These interventions may include many of those interventions listed previously. At each visit, the CNS should reevaluate the success of the interventions and make changes as the need arises.

From the present research, the CNS knows that the severity of fatigue does not rely on age, employment status or duration of caregiving. However, the CNS

also knows that those caregivers who are elderly either do not know about the various methods to decrease fatigue such as distraction or planned rest periods, or the caregivers have tried these methods and been unsuccessful for one reason or another to decrease the fatigue experienced. The CNS must then ascertain whether the caregiver knows of these methods and has tried them. If the caregiver isn't aware of these methods to decrease fatigue, the CNS should educate the caregiver as to the use of each of these methods and the best time to use them for optimal results.

The CNS also knows that those caregivers that work may not have time to utilize these fatigue reducing techniques, and so the CNS must explore with this caregiver how and when the caregiver might be able to utilize these techniques successfully given the role conflicts that exist between caregiver employment and the caregiving role. Therefore, the CNS must first determine the knowledge base of the caregiver regarding the various ways to alleviate fatigue, and then explore with the caregiver the options which may be available. For example, the CNS might suggest that the caregiver use planned rest periods following dinner, or the use of distraction techniques such as the caregiver watching his/her favorite comedy for one hour each night.

The principle of participation asserts that people are more likely to change and to maintain the change in behavior if they have participated actively in setting goals and strategies for change (King, 1981). Therefore, the CNS must first understand the concept of fatigue, its causes and effect upon the caregiver. She must then consider all the known characteristics and processes of care inherent to the caregiver and then design interventions mutually with the caregiver to alleviate the problem of fatigue. King (1981) states that individuals have a right to knowledge about themselves, to participate in their own health care decisions and

that nurses have the responsibility to share information that helps caregivers make informed decisions regarding their interventions and treatment.

Recommendations for Nursing Education

The nursing profession in general needs to develop appropriate interventions for those persons presenting with the complaint of fatigue. The concept of fatigue, in relation to nursing science, has not been included in most undergraduate or graduate nursing programs. Therefore, this concept needs to be included in the curriculum of nursing schools, along with appropriate interventions. One goal of education for the client is to increase the level of health knowledge concerning the importance of symptoms and the potential for treating the ailments. At the present time, the causative mechanisms of the fatigue phenomenon remain unknown. Interventions regarding this phenomenon must remain focused upon symptom management and relief. Therefore, nursing in general must thoroughly understand the nursing process with an emphasis upon assessment to adequately assess the components of caregiving with regard to the presenting complaint of fatigue. The nurse must assess both the characteristics of the caregiver and the processes of caregiving. The nurse at the ADN, BSN or MSN level should know specifically that the more daily care the caregivers render, the more fatigue will be experienced, and the more the caregiver's schedule is a burden to the caregiver, the greater the fatigue experienced. The CNS must also assess the older caregiver's knowledge base as to the self-care techniques for alleviating fatigue such as napping, pre-planned rest periods, use of distraction techniques and sleep to see if the caregiver is using these techniques properly or not at all. The nurse can then teach the proper methods to effectively combat fatigue to the caregiver.

The nurse should also assess the working caregiver to see if self-care techniques for alleviating fatigue can still be used considering the decreased amount of time that the caregiver has available with the increased number of conflicting roles the caregiver experiences.

Nursing at all levels must be increasingly cognizant of the problems of the caregiver. Further clarification and elaboration of adaptation to the role of the caregiver during various stages of cancer and other chronic diseases is needed. Nursing must be aware that the caregiver is not a silent observer, but as a member of the patient and caregiver dyad, both affects and is affected by the ill member's cancer.

Nursing must also be cognizant of the potential for caregiver fatigue, either as a reported or unreported problem. Though much more research needs to be conducted regarding the causes of fatigue, the effects of this phenomenon upon the body is well documented and various interventions exist to control the fatigue experienced by this population.

Nurses also need to know that before an intervention with a caregiver can be successful, both the caregiver and the nurse must mutually determine that the interventions can be successful (King, 1981). Therefore, a well designed program to effectively alleviate caregiver fatigue would include: a definition of the concept using a nursing theorist such as Piper's definition of fatigue, the nurse assessment of the characteristics of the caregiver and the processes of caregiving, measurement of the severity of fatigue using Piper's Self-Report Scale (items 1-12), determination of appropriate interventions based upon the characteristics of caregiving and the processes of caregiving and upon the caregiver's preference, and facilitation of the caregiver reaching these goals by the nurse.

Recommendations for Future Research

The concept of fatigue, acute and chronic, physically induced, physiologically induced, or psychologically induced needs to be researched further. Fatigue needs to be evaluated in different populations. Specifically, in the caregiver population, fatigue should be studied longitudinally from the beginning of the caregiver experience to possibly one year after the experience is over. By studying fatigue in this way, researchers could determine how fatigue changes as caregiving responsibilities increase, how fatigue changes with the death of the patient, and if and how fatigue is experienced in the adjustment to a non caregiving role. By studying fatigue in this way, and taking into account other variables such as those included in characteristics of the caregiver and the processes of care, other conflicting roles the caregiver has, and possible co-morbid conditions, health care providers could get a more realistic idea of the problem of caregiver fatigue, and the causes and effects of this concern. Perhaps better strategies could then be developed to deal with this complaint by conducting clinical trials with ways to alleviate and overcome fatigue.

The Piper Self-Report Scale measuring severity (items 1-12) has a good reliability and perhaps this scale can be further developed and refined for use in this population. However, further research for a different, possibly easier to use instrument should continue.

Because no research was found in which the relationship between caregiving age and fatigue was discussed, and because the population is aging and the number of caregivers of older persons will continue to increase, more research is necessary possibly considering such potential intervening variables as caregiver health, social isolation of the caregiver and depression. Another facet of caregiver fatigue not previously researched is the gender differences. Understanding how

male caregivers differ from female caregivers in dealing with caregiving demands and the accompanying fatigue will better enable the nurse to propose appropriate interventions.

The study proposed based upon the findings of this research would investigate and describe the experience of fatigue in the caregiver of the cancer patient and compare this experience to the fatigue experienced by the cancer patient. The study would be a two year longitudinal study with the caregiver completing the study over a two year period and the patient may or may not be able to complete the study. The methodology would include utilization of the Piper Self-Report Fatigue Scale (items 1-12) to be completed at bedtime every three months for two years for both populations. Included in both populations would be a measure of the number of roles each member of the dyad has, the number of hours of work outside the home performed by both members of the dyad, along with a consideration of the physical health of the caregiver. In this research, the difference between acute, normative and chronic fatigue in the caregiver would be described in different age groups, and fatigue could be examined over time to determine how the caregiver fatigue changes as caregiver demands increase, and how fatigue changes with the death of the spouse with the possibility of depression over the loss, but decrease in demands and role conflicts. Further, the CNS could set up an experimental design focusing on stress reduction activities for the caregivers. The interventions found to be most effective in alleviating fatigue could then be included in the nursing curriculum. In summary, much more research is needed to understand the phenomenon of fatigue both in the ill population and in the well population, specifically in the caregiver population.

Summary

In Chapter VI, a summary and interpretation of findings was presented. Findings were related to the conceptual framework of this study and the nursing theory. Recommendations for nursing practice, education and research were presented.

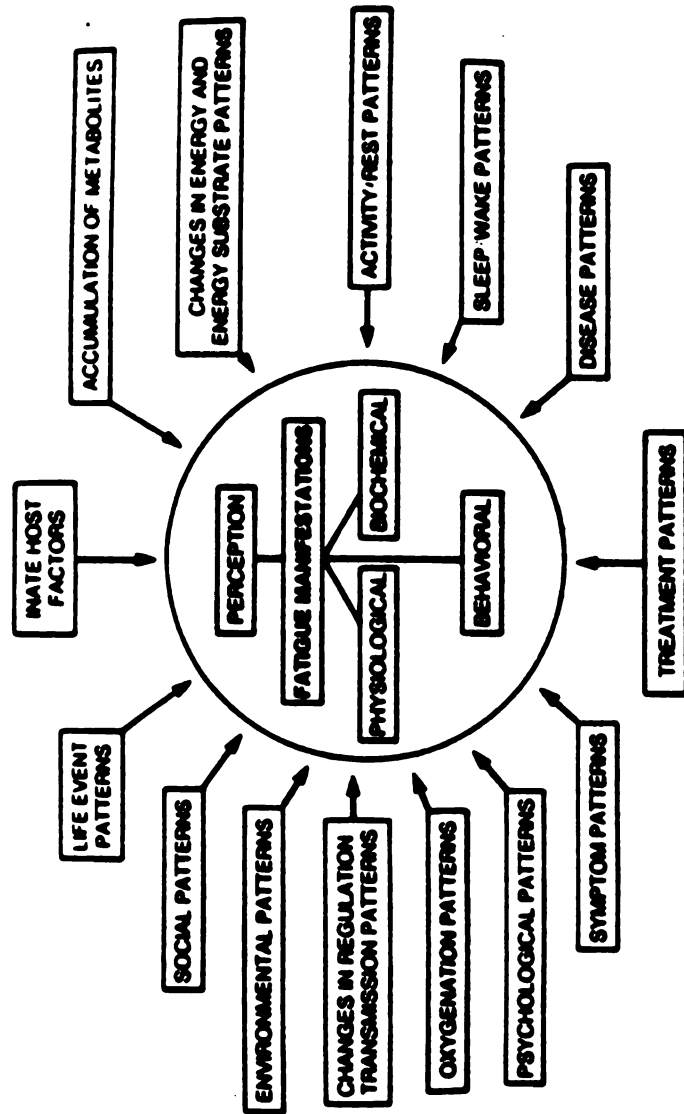
In Chapter VI, a content analysis of the data revealed that there was a relationship between the severity of caregiver fatigue and the impact upon the caregiver's schedule. There was also an inverse relationship between both caregiver age, employment status in relation to the ways to combat fatigue effectively.

The problems encountered with the research instruments were discussed and recommendations for future investigations were presented. Additionally, the findings were related to the conceptual framework and nursing theory as presented in the study with recommendations for nursing practice provided.

In summary, caregiver fatigue is a concept worthy of further, more indepth research. It is only with the results of research that health care professionals can hope to have a more positive impact on their patients, many of whom could be family caregivers of cancer patients.

APPENDICES

APPENDIX A



Fatigue framework for healthy and ill populations.

APPENDIX B

FATIGUE SELF-REPORT SCALE: BASELINE DATA

DIRECTIONS:

Each of the following questions addresses some activity or feeling which may be related to your fatigue. For each of these questions you will be asked to place an "X" through a line. This "X" should be placed through the exact spot on this line which best indicates the degree to which you are experiencing the activity or feeling. For example, if you really like to sleep late in the mornings, and you were asked the following question, you might answer:

1. To what degree do you usually like to sleep late in the mornings?

Not at all (Example) X A great deal

Another example would include the following: If you could only sleep late in the mornings on Saturday and Sunday, and you were asked the following question, you might answer:

2. How frequently are you able to sleep in the mornings during each week, including weekends?

Seldom X (Example) Often

PLEASE TURN THE PAGE AND BEGIN THE FOLLOWING QUESTIONNAIRE.

THANK YOU!

WAVE I

FATIGUE SELF-REPORT SCALE:
SHORT FORM CURRENT DATA

ID _____ 1-4
Card _____ 5-7
Date _____ 8-13
INT _____ 14-15
INT Code 1 16
Study 3 17

For each of the following questions, place an "X" through the line at the exact spot which best describes the fatigue you are experiencing now. If you are not now experiencing fatigue, describe what you experienced today.

1. To what degree are you experiencing fatigue now?
No fatigue _____ A great deal of fatigue 18 19
2. How severe is the fatigue which you are experiencing now?
No fatigue _____ A great deal of fatigue 20 21
3. How long have you been feeling fatigue?
Days _____ Weeks 22 23
4. How would you describe the fatigue which you are feeling now?
Intermittant _____ Continuous 24 25
5. To what degree has your fatigue changed in the past week?
Decreased _____ Increased 26 27

For each of the following questions, place an "X" through the line at the exact spot which best indicates the degree of distress or interference you are experiencing in today's activities as a result of your fatigue.

6. Is the degree of fatigue you are feeling causing you distress?
No distress _____ A great deal of distress 28 29
7. Overall, how much is the fatigue which you are experiencing now interfering with your ability to engage in the kind of activities you enjoy doing?
None _____ A great deal 30 31
8. How would you describe the degree of intensity or severity of the fatigue which you are experiencing now?
Mild _____ Severe 32 33

WAVE I

ID 1
Card 027Fatigue
Page 2

9. To what degree do you believe your family members' illness or disease is contributing or causing your fatigue?

Not at all _____ A great deal 34 35

10. To what degree do you believe your family members' medical treatment is contributing or causing your fatigue?

Not at all _____ A great deal 36 37

11. To what degree do you believe your personal illness (or disease) is contributing or causing your fatigue?

Not at all _____ A great deal 38 39

12. To what degree do you believe your personal medical treatment is contributing or causing your fatigue?

Not at all _____ A great deal 40 41

People who are fatigued may try certain activities to reduce the amount of fatigue they are experiencing. For each of the following questions, place an "X" through the line at the exact spot which best indicates the degree of relief each activity has provided you in reducing the amount of fatigue you have experienced today.

13. To what degree has sleep relieved your fatigue today?

No relief _____ Complete relief 42 43

14. To what degree have planned rest periods between activities relieved your fatigue today?

No relief _____ Complete relief 44 45

15. To what degree has exercise relieved your fatigue today?

No relief _____ Complete relief 46 47

16. To what degree has distraction relieved your fatigue today?

No relief _____ Complete relief 48 49

17. To what degree has lying down for short periods of time (napping) relieved you today?

No relief _____ Complete relief 50 51

WAVE I
Fatigue
Page 3

ID
Card 0 2 8

18. Overall, when you experienced fatigue today, the best thing you found which relieved your fatigue was: _____ 52

_____ 53

19. Overall, what do you believe is most directly contributing to or causing your fatigue? _____ 54

_____ 55

dls
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APPENDIX C

FATIGUE SELF-REPORT SCALE: BASELINE DATA

DIRECTIONS:

Each of the following questions addresses some activity or feeling which may be related to your fatigue. For each of these questions you will be asked to place an "X" through a line. This "X" should be placed through the exact spot on this line which best indicates the degree to which you are experiencing the activity or feeling. For example, if you really like to sleep late in the mornings, and you were asked the following question, you might answer:

1. To what degree do you usually like to sleep late in the mornings?

Not at all _____ (Example) _____ **X** _____ A great deal

Another example would include the following: If you could only sleep late in the mornings on Saturday and Sunday, and you were asked the following question, you might answer:

2. How frequently are you able to sleep in the mornings during each week, including weekends?

Seldom _____ **X** _____ (Example) _____ Often

PLEASE TURN THE PAGE AND BEGIN THE FOLLOWING QUESTIONNAIRE.

THANK YOU!

WAVE 1

FATIGUE SELF-REPORT SCALE:
SHORT FORM CURRENT DATA

ID _____ 1-4
Card _____ 5-7
Date _____ 8-13
INT _____ 14-15
INT Code 1 16
Study 3 17

For each of the following questions, place an "X" through the line at the exact spot which best describes the fatigue you are experiencing now. If you are not now experiencing fatigue, describe what you experienced today.

1. To what degree are you experiencing fatigue now?
No fatigue _____ A great deal of fatigue 18 19
2. How severe is the fatigue which you are experiencing now?
No fatigue _____ A great deal of fatigue 20 21
3. How long have you been feeling fatigue?
Days _____ Weeks 22 23
4. How would you describe the fatigue which you are feeling now?
Intermittant _____ Continuous 24 25
5. To what degree has your fatigue changed in the past week?
Decreased _____ Increased 26 27

For each of the following questions, place an "X" through the line at the exact spot which best indicates the degree of distress or interference you are experiencing in today's activities as a result of your fatigue.

6. Is the degree of fatigue you are feeling causing you distress?
No distress _____ A great deal of distress 28 29
7. Overall, how much is the fatigue which you are experiencing now interfering with your ability to engage in the kind of activities you enjoy doing?
None _____ A great deal 30 31
8. How would you describe the degree of intensity or severity of the fatigue which you are experiencing now?
Mild _____ Severe 32 33

WAVE I

ID 1
Card 0 2 7Fatigue
Page 2

9. To what degree do you believe your family members' illness or disease is contributing or causing your fatigue?

Not at all _____ A great deal 34 35

10. To what degree do you believe your family members' medical treatment is contributing or causing your fatigue?

Not at all _____ A great deal 36 37

11. To what degree do you believe your personal illness (or disease) is contributing or causing your fatigue?

Not at all _____ A great deal 38 39

12. To what degree do you believe your personal medical treatment is contributing or causing your fatigue?

Not at all _____ A great deal 40 41

People who are fatigued may try certain activities to reduce the amount of fatigue they are experiencing. For each of the following questions, place an "X" through the line at the exact spot which best indicates the degree of relief each activity has provided you in reducing the amount of fatigue you have experienced today.

13. To what degree has sleep relieved your fatigue today?

No relief _____ Complete relief 42 43

14. To what degree have planned rest periods between activities relieved your fatigue today?

No relief _____ Complete relief 44 45

15. To what degree has exercise relieved your fatigue today?

No relief _____ Complete relief 46 47

16. To what degree has distraction relieved your fatigue today?

No relief _____ Complete relief 48 49

17. To what degree has lying down for short periods of time (napping) relieved you today?

No relief _____ Complete relief 50 51

APPENDIX D

APPENDIX D

1. My activities are centered around caring for _____.
2. I have to stop in the middle of my work or activities to provide care.
3. I have eliminated things from my schedule since caring for _____.
4. The constant interruptions make it difficult to find time for relaxation.
5. I visit family and friends less since I have been caring for _____.

APPENDIX E

FATIGUE SELF-REPORT SCALE: BASELINE DATA

DIRECTIONS:

Each of the following questions addresses some activity or feeling which may be related to your fatigue. For each of these questions you will be asked to place an "X" through a line. This "X" should be placed through the exact spot on this line which best indicates the degree to which you are experiencing the activity or feeling. For example, if you really like to sleep late in the mornings, and you were asked the following question, you might answer:

1. To what degree do you usually like to sleep late in the mornings?

Not at all _____ (Example) X A great deal

Another example would include the following: If you could only sleep late in the mornings on Saturday and Sunday, and you were asked the following question, you might answer:

2. How frequently are you able to sleep in the mornings during each week, including weekends?

Seldom X _____ (Example) Often

FATIGUE SELF-REPORT SCALE: BASELINE DATA

SUBJECT NUMBER _____

Clinical Site Codes: 1 2 3 4 5

DATE ____ / ____ / ____

TIME NOW ____ / ____
(Hour) (Minutes)

For each of the following questions, place an "X" through the line at the exact spot which best describes your usual pattern of fatigue.

1. When during the morning are you most likely to experience fatigue?
1 A.M. _____ 12 Noon _____
2. When during the afternoon/evening are you most likely to experience fatigue?
1 P.M. _____ 12 Midnight _____
3. How frequently do you usually experience fatigue?
Seldom _____ Often _____
4. How long do you usually experience fatigue?
Minutes _____ Hours _____
5. _____ Days _____ Weeks _____
6. How would you describe your usual pattern of fatigue?
Intermittent _____ Continuous _____
7. _____ Acute _____ Chronic _____
8. Localized _____ Generalized _____
(To a specific muscle group/extremity) (Whole body is fatigued)
9. To what degree has your usual pattern of fatigue changed during the past six months?
Decreased _____ Increased _____

For each of the following questions, place an "X" through each line at the exact spot which best indicates the degree of distress or interference you usually experience in your daily activities as a result of your fatigue.

10. The degree of distress you usually experience in your daily activities as a result of your fatigue is:
No Distress _____ A great deal of distress _____
11. How much does the fatigue you usually experience interfere with your ability to clean your house?
None _____ A great deal _____
12. How much does the fatigue you usually experience interfere with your ability to cook for yourself?
None _____ A great deal _____

13. How much does the fatigue you usually experience interfere with your ability to bathe or wash yourself?
None _____ A great deal
14. How much does the fatigue you usually experience interfere with your ability to read?
None _____ A great deal
15. How much does the fatigue you usually experience interfere with your ability to dress yourself?
None _____ A great deal
16. How much does the fatigue you usually experience interfere with your ability to complete your work or school activities?
None _____ A great deal
17. How much does the fatigue you usually experience interfere with your ability to visit or socialize with your friends?
None _____ A great deal
18. How much does the fatigue you usually experience interfere with your ability to engage in sexual activity?
None _____ A great deal
19. Overall, how much does the fatigue you usually experience interfere with your ability to engage in the kind of activities you enjoy doing?
None _____ A great deal
20. Overall, how would you describe the intensity or severity of the fatigue you usually experience?
Mild _____ Severe
21. To what degree would you describe the fatigue you usually experience as being:
Pleasant _____ Unpleasant
22. Agreeable _____ Disagreeable
23. Protective _____ Destructive
24. Positive _____ Negative
25. Normal _____ Abnormal
26. To what degree do you believe illness or disease usually contributes to or causes your fatigue?
Not at all _____ A great deal
27. To what degree do you believe medical treatment usually contributes to or causes your fatigue?
Not at all _____ A great deal

28. To what degree do you believe the lack of adequate sleep usually contributes to or causes your fatigue?
Not at all _____ A great deal
29. To what degree do you believe the lack of adequate rest usually contributes to or causes your fatigue?
Not at all _____ A great deal
30. To what degree do you believe the lack of exercise usually contributes to or causes your fatigue?
Not at all _____ A great deal
31. To what degree do you believe too much noise usually contributes to or causes your fatigue?
Not at all _____ A great deal
32. To what degree do you believe too much work usually contributes to or causes your fatigue?
Not at all _____ A great deal
33. To what degree do you believe too much stress usually contributes to or causes your fatigue?
Not at all _____ A great deal
34. To what degree do you believe eating too little usually contributes to or causes your fatigue?
Not at all _____ A great deal
35. To what degree do you believe depression usually contributes to or causes your fatigue?
Not at all _____ A great deal
36. To what degree do you believe too much exercise usually contributes to or causes your fatigue?
Not at all _____ A great deal
37. To what degree do you believe eating too much usually contributes to or causes your fatigue?
Not at all _____ A great deal
38. Overall, what do you believe most directly contributes to or causes the fatigue you usually experience? _____

People feeling fatigued may experience certain feelings which indicate to them that they are fatigued. For each of the following questions, place an "X" through the line at the exact spot which best indicates the degree to which each feeling generally is experienced by you when you are fatigued.

39. When I am fatigued, I usually feel:
Refreshed _____ Exhausted
40. When I am fatigued, I usually feel:
Strong _____ Weak
41. When I am fatigued, I usually feel:
Awake _____ Sleepy
42. When I am fatigued, I usually feel:
Lively _____ Listless
43. When I am fatigued, I usually feel:
Alert _____ Drowsy
44. When I am fatigued, I usually feel:
Refreshed _____ Tired
45. When I am fatigued, I usually feel:
Energetic _____ Unenergetic
46. When I am fatigued, I usually feel:
Vigorous _____ Sluggish
47. When I am fatigued, I usually feel:
Interested _____ Bored
48. When I am fatigued, I usually feel:
Calm _____ Nervous
49. When I am fatigued, I usually feel:
Patient _____ Impatient
50. When I am fatigued, I usually feel:
Motivated _____ Unmotivated
51. When I am fatigued, I usually feel:
Happy _____ Sad
52. When I am fatigued, I usually feel:
Relaxed _____ Tense

53. When I am fatigued, I usually feel:
 Exhilarated _____ Depressed
54. When I am fatigued, I usually feel:
 Able to _____ Unable to
 Concentrate _____ Concentrate
55. When I am fatigued, I usually feel:
 Able to _____ Unable to
 Remember _____ Remember
56. When I am fatigued, I usually feel:
 Able to _____ Unable to
 Think clearly _____ Think clearly
57. Are there other feelings that you experience when you are fatigued?
 (1) No ☐
 (2) Yes ☐ Please describe _____

When people feel fatigued they also may experience other signs or symptoms. For each of the following signs and symptoms, place an "X" through the line at the exact spot which best indicates the degree to which each sign or symptom is experienced when you are fatigued.

58. When I am fatigued, I usually am in pain.
 No pain _____ Severe pain
59. When I am fatigued, I usually have a headache.
 No Headache _____ Severe Headache
60. When I am fatigued, I usually am nauseated (sick to my stomach).
 No Nausea _____ Severe Nausea
61. When I am fatigued, I usually vomit (throw up).
 No vomiting _____ Severe vomiting
62. When I am fatigued, I usually have eye strain.
 No eye strain _____ Severe eye strain
63. When I am fatigued, I usually am constipated (hard, infrequent bowel movements).
 No _____ Severe
 Constipation _____ Constipation
64. When I am fatigued, I usually have diarrhea (loose, frequent bowel movements).
 No diarrhea _____ Severe diarrhea
65. When I am fatigued, I usually have shortness of breath.
 No shortness _____ Severe shortness
 of breath _____ of breath

66. When I am fatigued, I usually have difficulty in breathing.
 No difficulty _____ Severe difficulty _____
67. When I am fatigued, I usually am coughing.
 No coughing _____ Severe coughing _____
68. When I am fatigued, I usually have a fever.
 No fever _____ Severe fever _____
69. Do you experience any other symptoms when you are fatigued?
 (1) No ☐
 (2) Yes ☐ Please describe _____

People who are fatigued may try certain activities to reduce the amount of fatigue they are experiencing. For each of the following questions, place an "X" through the line at the exact spot which best indicates the degree of relief each activity usually provides you in reducing the amount of fatigue.

70. To what degree does sleep usually relieve your fatigue?
 No relief _____ Complete relief _____
71. To what degree do planned rest periods between activities usually relieve your fatigue?
 No relief _____ Complete relief _____
72. To what degree does exercise usually relieve your fatigue?
 No relief _____ Complete relief _____
73. To what degree does distraction usually relieve your fatigue?
 No relief _____ Complete relief _____
74. To what degree does eating usually relieve your fatigue?
 No relief _____ Complete relief _____
75. To what degree does lying down for short periods of time (napping) usually relieve your fatigue?
 No relief _____ Complete relief _____
76. Overall, when you experience fatigue, the best thing you can do to relieve your fatigue is:

77. To what degree are you experiencing fatigue now?
 No fatigue _____ A great deal of fatigue _____
78. How severe is the fatigue which you are experiencing now?
 No fatigue _____ Worst fatigue ever experienced _____

79. How would you describe your current fatigue?

Localized _____ Generalized
(To a specific muscle group/extremity) (Whole body is fatigued)

80. Is there anything else you would like to add that would describe your fatigue better to us?

81. This is the last question we would like to ask you. Do the words "tired" and "fatigued" mean the same to you or do they have different meanings? (There are no right or wrong answers. Your response will simply add to our understanding about fatigue experience.) Thank you.

82. Time Now: _____ / _____
(Hours) (Minutes)

T₁ T₂ T₃ T₄ T₅ T₆

FATIGUE SYMPTOM CHECKLIST

SUBJECT NUMBER _____

Clinical Site Code: 1 2 3 4 5

DATE ____/____/____

TIME NOW ____/____
(Hour) (Minutes)

PLEASE CIRCLE ONLY ONE NUMBER FOR EACH OF THE FOLLOWING SYMPTOMS

At the moment I feel	Absence of	A Little	Moderate Amount	Quite A Bit	A Great Deal
1. Heavy headed	1	2	3	4	5
2. Tired over my whole body	1	2	3	4	5
3. Tired in my legs	1	2	3	4	5
4. Like yawning	1	2	3	4	5
5. My thoughts are muddled	1	2	3	4	5
6. Drowsy	1	2	3	4	5
7. Eye strain	1	2	3	4	5
8. Awkward or clumsy	1	2	3	4	5
9. Unsteady on my feet	1	2	3	4	5
10. Want to lie down	1	2	3	4	5
11. Difficulty thinking	1	2	3	4	5
12. Tired of talking	1	2	3	4	5
13. Nervous	1	2	3	4	5
14. Unable to concentrate	1	2	3	4	5
15. Unable to take interest in things	1	2	3	4	5
16. Forgetful	1	2	3	4	5
17. Lacking in self-confidence	1	2	3	4	5
18. Anxious	1	2	3	4	5
19. I can't straighten my posture	1	2	3	4	5
20. Impatient	1	2	3	4	5
21. A headache	1	2	3	4	5
22. Stiff shoulders	1	2	3	4	5
23. Back pain	1	2	3	4	5
24. Difficulty breathing	1	2	3	4	5
25. Thirsty	1	2	3	4	5
26. Voice is husky	1	2	3	4	5
27. Dizzy	1	2	3	4	5
28. Twitching eyes	1	2	3	4	5
29. Twitching limbs	1	2	3	4	5
30. Feel ill	1	2	3	4	5
31. Time Now: _____ (Hour) (Minutes)					

DEMOGRAPHIC PROFILE

SECTION A: TO BE COMPLETED BY THE REGISTERED NURSE

Subject Number: _____

Clinical Site Code: 1 2 3 4 5

Medical Record Number: _____

Date of Entry: ____/____/____
(Month) (Day) (Year)

SECTION B: TO BE COMPLETED BY THE SUBJECT

DIRECTIONS:

Time Now ____/____
(Hour) (Minutes)

For each of the following questions you will be asked to either 1) fill in the blank or 2) place a check mark (✓) in the appropriate space. For each question, please select the one best response.

1. Birthdate: ____/____/____
(Month) (Day) (Year)
2. Age in years: _____
3. Sex (1) Male _____
(2) Female _____
4. Ethnic Background:
(1) Caucasian: _____
(2) Mexican-American: _____
(3) Oriental: _____
(4) Black: _____
(5) Other (Specify): _____
5. Marital Status:
(1) Single, Never Married: _____
(2) Married: _____
(3) Separated/Divorced: _____
(4) Widowed: _____

APPENDIX F

MICHIGAN STATE UNIVERSITY

UNIVERSITY COMMITTEE ON RESEARCH INVOLVING
HUMAN SUBJECTS (UCRIHS)
205 BERRY HALL
(517) 353-0730

EAST LANSING • MICHIGAN • 48824-1111

December 5, 1989

IRB# 89-522

Susan Jensen
846 W. Thomas L Parkway
Lansing, MI 48917

Dear Ms. Jensen:

RE: "THE RELATIONSHIP BETWEEN FATIGUE IN THE CAREGIVER OF THE
CANCER PATIENT AND CAREGIVER CHARACTERISTICS AND PROCESS
OF CARE IRB# 89-522"

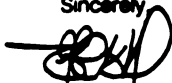
The above project is exempt from full UCRIHS review. I have reviewed the proposed research protocol and find that the rights and welfare of human subjects appear to be protected. You have approval to conduct the research.

You are reminded that UCRIHS approval is valid for one calendar year. If you plan to continue this project beyond one year, please make provisions for obtaining appropriate UCRIHS approval one month prior to December 5, 1990.

Any changes in procedures involving human subjects must be reviewed by UCRIHS prior to initiation of the change. UCRIHS must also be notified promptly of any problems (unexpected side effects, complaints, etc.) involving human subjects during the course of the work.

Thank you for bringing this project to our attention. If we can be of any future help, please do not hesitate to let us know.

Sincerely,



John K. Hudzik, Ph.D.
Chair, UCRIHS

JKH/sar

cc: B. Given

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