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thesis entitled

The Impact of Caregiver Symptom Involvement on Levels of Perceived Preparedness in Caregivers for Elderly, Terminally Ill Cancer Patients

presented by

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has been accepted towards fulfillment
of the requirements for

Masters degree in Nursing

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Date 4/27/98

THE IMPACT OF CAREGIVER SYMPTOM INVOLVEMENT ON LEVELS OF PERCEIVED PREPAREDNESS IN CAREGIVERS FOR ELDERLY, TERMINALLY ILL CANCER PATIENTS

By

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A THESIS

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

MASTER OF SCIENCE IN NURSING

College of Nursing

1998

ABSTRACT

THE IMPACT OF CAREGIVER SYMPTOM INVOLVEMENT ON LEVELS OF PERCEIVED PREPAREDNESS IN CAREGIVERS FOR ELDERLY, TERMINALLY ILL CANCER PATIENTS

By

Sharon L. Kozachik

As terminal cancer care moves from the formal to the home setting, family caregivers are faced with the tasks of managing palliative care modalities and untoward effects of terminal cancer. The objective of this research is to determine how levels of caregiver involvement in symptom management impacts his/her perceived preparation to care, and if caregiver gender or living arrangements impacts his/her perceived preparation to care. This secondary analysis utilized a sample of caregivers whose elderly patients, newly diagnosed with cancer, died while participating in a longitudinal study. Participants were accrued by convenience sampling and gave informed consent. Symptom management and preparedness measures were obtained through telephone interviews and self-administered questionnaires. Data analysis were conducted using multiple regression models. The impact that the independent variables had on the dependent variable was not statistically significant. Nurses in advanced practice must assess caregivers for previous helping behaviors and communication patterns with their patients.

This work is dedicated to my husband, Tom, who encouraged my academic endeavors, read drafts of every required course paper, graciously allowed numerous practice physical assessments, and never complained when the house was messy.

ACKNOWLEDGMENTS

The attainment of a goal is rarely the result of a singular effort. This author gratefully acknowledges the insights, assistance, wisdom, and support of her thesis committee chair, Dr. Barbara Given. She has been generous with her time, knowledge, and energy to facilitate my professional and student development, and she has been one of my role models. Thank you for believing in my abilities.

Gratitude is also due to Dr. C. William Given, one of my thesis committee members, for his thoughtful and insightful input, and support of this scholastic endeavor. He has provided me with numerous learning experiences beyond the scope of this thesis and has encouraged me to broaden my academic horizons.

Finally, gratitude is due to Dr. Clare Collins, my other thesis committee member, who provided much conceptual input and constructive comments during the developmental phase of this thesis. Her lectures and research are inspiring, and she has also been one of my role models.

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INTRODUCTION

Cancer is a disease of the aging, with 67% of cancer deaths occurring after the age of 65 (American Cancer Society, 1995). This cohort is the most rapidly growing segment of the population (Kart, Metress, & Metress, 1992). Thus, there are growing numbers of persons being diagnosed and treated for cancer. As health care provision is shifted from the institutional setting to outpatient and home settings (Mor, Guadagnoli, & Wool, 1988), and patients are discharged `sicker and quicker', greater numbers of family members are being thrust into the role of caregiver. Further, as cancer patients grow more frail, they become much more dependent upon family members for assistance with personal care tasks (dressing and bathing), instrumental care tasks (shopping, cooking, and household activities), administrative needs (acquiring medical care equipment and consumable medical supplies, acting as an advocate with insurance companies) (Mor, Guadagnoli, & Wool, 1988), and management of symptoms.

Families assume these care tasks with little training in the management of symptoms associated with either the cancer illness or the treatment modality, or education regarding the disease process or trajectory. Many caregivers assume this role without previous caregiving experience. If the patient is diagnosed in the advanced stage of cancer, then family caregivers are forced to manage complex patterns of symptoms for their patients, while recognizing their patients' terminal illness status. Family caregivers are profoundly affected by the patients' disease. Beyond the emotional upheaval that occurs, there are also great amounts of disruption to the caregivers' personal, professional, and social roles, as well as reassignment of family roles and obligations. How to best prepare family caregivers to be involved in managing symptoms, in light of the emotional experiences that accompany terminal diagnoses, remains the greatest challenge for health care professionals. Therefore, this research will address how the caregiver's involvement in symptom management will impact his/her perceived preparation to care for a newly diagnosed, elderly cancer patient.

Background of the Problem

For patients diagnosed with cancer, there are three possible goals: curing the disease, increasing survival time, or improving quality of life. For terminally ill cancer patients, palliation becomes the goal, and improving the quality of the patient's life becomes the most important outcome. Palliative care methods include chemotherapy, radiation therapy, surgical resection, or no treatment other than comfort measures, such as pain control. Chemotherapy and/or radiation treatment may decrease the tumor burden, slow the tumor growth, or prevent the tumor from increasing in size. The ultimate goal of these treatment modalities is to increase the quality of life for the terminally ill patient. However, the untoward effects from these treatment modalities are numerous and their management can be difficult. Nausea, vomiting, fatigue, insomnia, pain, loss of appetite, difficulty breathing, and behavioral/mood changes are a few examples of the sequelae of terminal cancer illnesses and the palliative therapies utilized to facilitate increased quality of life and comfort for the patients.

Although many studies have examined the relationship between caregiver burden and psychosocial disequilibrium (Pruchno, 1990; Moen, Robison, & Dempster-McClain, 1995; Aneshensel, Pearlin, & Schuler, 1993; Stommel, Given, & Given, 1990; Schulz, Visintainer, & Williamson, 1990), few, if any researchers, have looked at the caregiver's involvement in rendering care to a patient, and how this impacts the caregiver's perceived preparation to care at any phase of the terminal illness.

What has also not been addressed in the literature is how the caregiver's perception of the patient's experiences with symptoms and/or the degree to which the caregiver is involved in managing the patient's symptoms, impacts the caregiver's perceived preparation to care. If a caregiver is rendering symptom management assistance to a patient who he/she perceives is experiencing six cancer or treatment related symptoms, and is involved in managing all six, how does this caregiver's response differ from the caregiver who is rendering symptom management assistance to a patient who he/she perceives is experiencing fifteen cancer or treatment related symptoms, and is involved in managing only seven of those symptoms. Do they perceive their preparation to care similarly, despite the differences in their recognition of, and involvement in, their patients' experiences with symptoms? Or, do caregivers' experiences differ, and if so, which caregiver reports greater perceived levels of preparedness in relation to his/her involvement in recognized symptom management, the caregiver who manages a greater or lesser proportion of recognized symptoms?

This research examines the level of caregivers' involvement in the management of symptoms for their patients' with terminal lung, colorectal, breast, or prostate cancer, and how the involvement in symptoms impacts caregivers' perceived levels of preparedness to care.

Family members who take on the caregiving role do so, often times, without prior knowledge or training in the tasks of caregiving. If health care provision continues with the trend toward fewer inpatient hospital days, same day surgeries, and outpatient chemotherapy and radiation therapy, then health care providers must be called upon to ensure that their patients are being released to caregivers who are mentally and physically prepared to provide the requisite care needs. In addition, caregivers must be educated regarding the disease process and trajectory, and trained in the art and science of managing the sequelae of not only the terminal cancer illnesses, but also the palliative treatment modalities.

The information gleaned from this study can be utilized by advanced practice nurses and other health care professionals to develop, implement, and evaluate caregiver educational/training programs and caregiver support groups. The development and implementation of educational and supportive groups for caregivers of terminally ill patients will have a domino effect; caregivers will benefit from the nurturing support network and knowledge attainment regarding the illness trajectory of a terminal cancer, as well as the management of symptoms that accompany a terminal cancer illness. The terminally ill cancer patients will benefit by having caregivers who are knowledgeable about their illnesses and disease trajectories. Terminally ill cancer patients will also benefit by having caregivers who have knowledge regarding the means to most effectively manage the ever changing symptom constellations that accompany the terminal cancer and the various methods of treatment utilized to improve the patients' quality of life.

Terminally ill cancer patients have the potential to experience greater levels of physical and psychological comfort if they have caregivers who are prepared to assume the complex and time consuming tasks required to manage their symptoms. Physical and psychological comfort in patients are the goals of all health care providers, regardless of the practice setting. Why should health care goals be any different merely because the health care provider is now a lay person, generally a family member or friend, and the care provision is in a home setting? Educated and supported caregivers, be they lay or professional, should be more prepared to facilitate physical and psychological comfort in their terminally ill cancer patients, thus health care providers must explore this avenue in order to enhance patient care and effect quality outcomes for both patient and caregiver.

Problem Statement

Family members are assuming caregiving roles with little to no education, support, or preparation from the formal health care system. The complexities involved in providing health care in the home setting to terminally ill cancer patients pose an even greater challenge when chemotherapy, radiation therapy, and/or palliative care modalities are prescribed to provide comfort to, and improve the quality of life for, these patients.

The purpose of this study is to determine how the level of caregiver involvement in symptom management at the last interview wave completed prior to the patient's death impacts the caregiver's report of perceived preparedness to care.

The research questions to be answered are:

1. During the period prior to the patient's death, is it the number of symptoms the caregiver reported that the patient experienced, the number of symptoms that the caregiver was involved in managing, or the proportion of symptoms reported by the caregiver that the caregiver was involved in managing that predicts caregiver perceived preparedness?
2. How does the caregiver's gender and living arrangements further impact the caregiver's perceived preparedness?

Definitions

Cancer Sites. Lung cancer was estimated to be diagnosed in 178,100 people in 1997, accounting for 13% of all cancer diagnoses, and an estimated 160,400 deaths occurred due to lung cancer (American Cancer Society, 1997). Lung is the most common site for both cancer incidence and mortality. The 5-year survival rate for late staged lung cancer is only 2% (American Cancer Society, 1997).

Colorectal cancer was estimated to be diagnosed in 131,200 people in 1997, accounting for approximately 9% of the new cancer diagnoses, and an estimated 54,900 colorectal cancer deaths occurred in 1997, accounting for about 10% of all cancer deaths (American Cancer Society, 1997). Colorectal cancer is second to lung cancer in mortality, with late staged colorectal patients who have distant metastasis having a 5-year survival rate of only 7% (American Cancer Society, 1997).

Approximately 181,600 new diagnoses of breast cancer were made in 1997, with 1,400 of those diagnosed being males, and an estimated 44,190 breast cancer deaths occurred (American Cancer Society, 1997). Late staged breast cancer patients who have distant metastasis have a 5-year survival rate of 20% (American Cancer Society, 1997).

It has been estimated that 334,500 new cases of prostate cancer were diagnosed in 1997, with 41,800 prostate cancer deaths occurring (American Cancer Society, 1997). Late staged prostate cancer has a 5-year survival rate of 30% (American Cancer Society, 1997).

When looking at lung, colorectal, breast, and prostate cancer as a group, it is noted that in 1997 there was expected to be a combined total of 825,400 new cases diagnosed, with 301,290 anticipated fatalities due to these four types of cancer. The American Cancer Society (1997) estimated that there would be 1,382,400 new cancer diagnoses (all types) with 560,000 deaths due to all cancer types in 1997. Lung, colorectal, breast, and prostate cancers accounted for 60% of all newly diagnosed cancers and 54% of all cancer deaths in 1997. Because these four cancer sites accounted for more than half of all newly diagnosed cancers and cancer deaths in 1997, it is important to understand and learn from the experiences of not only the cancer patients, but also their caregivers.

Symptoms Associated with Terminal Cancer and Cancer Treatments

Hegyvary (1993) defined symptoms as the perceived indicators of change in normal functioning as experienced by patients. The symptoms associated with terminal cancer include: Pain, nausea, anorexia, problems of infection, bleeding, insomnia, fatigue, headache, difficulty breathing, poor appetite, weight loss, cough, and mood changes (American Cancer Society, 1995).

Symptoms associated with chemotherapy include: Fatigue, nausea, loss of hair, vomiting, diarrhea, poor appetite, weight loss, fever, dry mouth, mouth sores, change in taste, bouts of perspiration, itching, bleeding/bruising, and mood changes (Dodd, 1987). Radiation therapy can cause the patient to experience skin irritation and/or burning at the irradiation site, fatigue, pneumonitis, and enteritis (American Cancer Society, 1995). Surgical resection of the tumor can cause the patient to experience pain at the surgical site, as well as fatigue, weakness, and insomnia.

Caregiver Involvement in Symptom Management

Managing the myriad of symptoms that accompanies terminal cancer and its palliative treatment modalities can be a daunting task, even for an experienced health care provider. Hegyvary (1993) described symptom management as part of comprehensive health care that aims to treat both disease and the manifestations of illness. Caregiver involvement in symptom management is not a static entity, rather involvement ebbs and flows as patients are able to participate to greater or lesser degrees in their own symptom management.

Perceived Preparation to Care

Caregivers can be exposed to much education, training, and supportive networks, yet still feel ill-prepared to provide care to their loved ones (Rusniak & Murphy, 1995). Is it attitude, cognition, or a combination of the two that impacts the degree to which caregivers feel prepared to care for their terminally ill cancer patients? Archbold, Stewart, Greenlick, and Harvath (1990) viewed caregiving as a role, and as such, explored how caregivers not only learned the multiple facets of the caregiving role, but also how caregivers evaluated their ability to fulfill this multifaceted role. Their concept of preparedness was domain specific, and related to things such as feeling prepared to care for physical needs; to care for emotional needs; planning for meals, rest, and recreation; and to help in the management of symptoms.

Schumacher, Stewart, and Archbold (1998) refined the original preparedness definition, analogizing preparedness to readiness. They discussed its origin from role theory, as well as how the various dimensions within the original preparedness instrument refer to the corresponding caregiver role domains.

Preparedness can have different meanings to different caregivers. One caregiver may perceive him/her self as prepared to care because of specialized knowledge and skills. A second caregiver may perceive him/her self as prepared to care because of a strong sense of commitment to, and love for, the care recipient. A third caregiver may perceive him/her self prepared to care because of religious or moral/ethical values. Although all of these caregivers perceive themselves as prepared to care, the perspectives from which they base their perceived preparedness are vastly different. Beyond the caregiver's perceived preparedness to provide care, the caregiver must also consider his/her perceived preparedness in relation to their patients' terminal status. Caregivers are faced with the knowledge that their loved ones will die, despite the care that is rendered, and are forced to question their preparedness within the context of death as the outcome.

Mastery is the control caregivers feel they are able to impose over other forces that affect their lives; it attributes patients' outcomes to the caregivers' abilities and efforts (Aneshensel, Pearlin, Mullan, Zarit, & Whitlach, 1995). Lawton, Kleban, Moss, Rovine, and Glicksman (1989) view caregiving mastery as the positive view of the caregiver's ability and ongoing behavior during the caregiving process; it is a self-perception that stems from the occurrences during the course of caregiving. Although preparedness and mastery are concepts that address the caregiver role-taking from the caregiver's's perception, they address two separate issues. One can perceive preparedness to care and not necessarily perceive a sense of mastery over the role.

Benner (1984) speaks of the role evolution from novice to expert. The novice has had no experience of the situation in which he/she is expected to perform, thus the beginner is provided with rules by which to operate. The expert is a polar opposite of the novice; rules that govern actions are replaced by intuitive actions. The expert operates from a global grasp of the situation at hand. Since many caregivers enter the caregiving situation as a novice, they may require numerous rules and education/training sessions to guide them in their quests for managing the complex symptoms that arise in their patients.

The blending of the concept preparedness along with Benner's (1984) role evolution of novice to expert, provides the basis for the definition of preparedness for this paper. Caregiver preparedness is developed through experiential knowledge; the caregiver perceives preparedness <u>after</u> being engaged in and experiencing the caregiver role task of involvement in managing symptoms.

Because terminal cancer care can be both physically and emotionally exhausting work, it is imperative that caregivers perceive that they are prepared to handle the fluid nature of the patient's abilities to provide self-care, as well as the physical and psychosocial sequelae of the disease process.

Terminal Cancer

An advanced, progressive cancer that does not respond to active treatment modalities, such as chemotherapy or radiation therapy, is termed terminal (American Cancer Society, 1995). Ham and Sloane (1997) define terminal illness as one where the patient's life expectancy is six months or less.

If the assumption is correct that each newly diagnosed, terminally ill lung, colorectal, breast, and prostate cancer patient had an involved caregiver in 1997, then there were 301,290 newly tenured caregivers last year. Terminally ill cancer patients experience numerous untoward effects from the illness and the treatment modality(ies) used, often occurring in symptom clusters. The caregivers who are in charge of the day to day management of these terminally ill patients do so at various levels of physical, psychological, and educational preparation.

Conceptual Framework

The assumption of this study is that the level of a caregiver's involvement in symptom management for an elderly, terminally ill, cancer patient will impact the level of the caregiver's perceived preparation to care. The conceptual model used to guide this study is adapted from the Social Cognitive Theory developed by Bandura (1986). Bandura (1986) developed this theory of human motivation and action based on the concept of triadic reciprocality: The belief that behavioral factors, cognitive/personal factors, and environmental factors act and react with the others in a mutual, but not necessarily equal, manner (see Figure 1). Behavioral factors include the person's physical action(s). Cognitive/personal factors include thoughts, feelings, values, attitudes, motives, knowledge, problem-solving, and self-efficacy. Environmental factors include social sublets, role relationships, family/household membership, socioeconomic status, and social institutions. Because individuals have unique behavioral, cognitive/personal, and environmental factors, the action/reaction potentials of each individual's triad will vary.

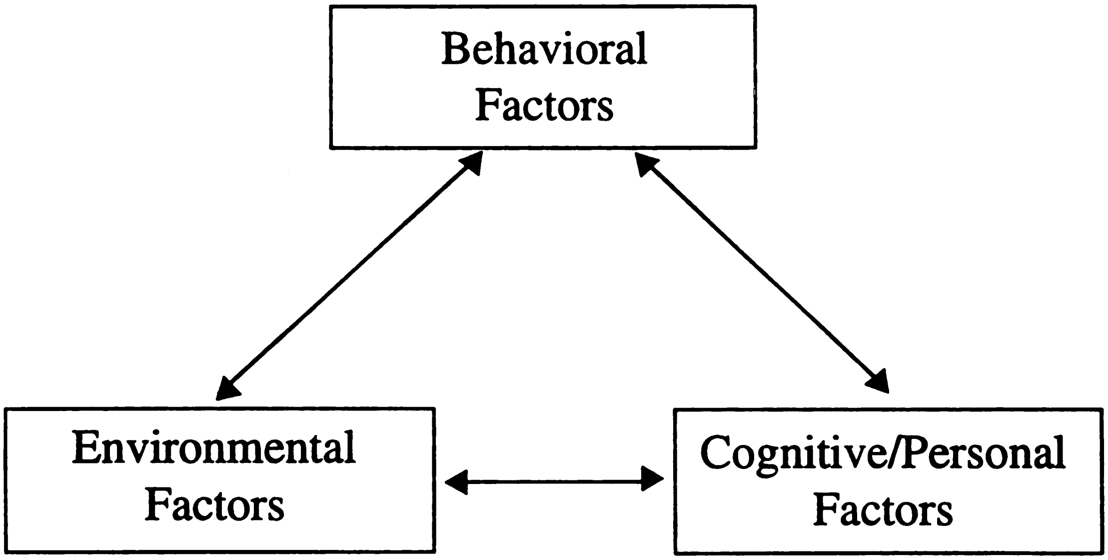

Figure 1. Social Cognitive Theory, Bandura (1986).

The conceptual model utilized in this study deviates from the Bandura model, in that the premise claims that the caregiver's environmental factors will act upon the caregiver's behavioral factors, and that the caregiver's behavioral factors will impact his/her cognitive/personal factors. This study examines how the level of caregiver involvement in symptom management impacts the level of perceived preparation to care for the caregiver for a terminally ill, elderly cancer patient (see Figure 2).

Cancer in the terminal phase will present with similar symptom constellations, namely pain, fatigue, dyspnea, anorexia, and insomnia (Lynn, Teno, Phillips, Wu, Desbiens, Harrold, Claessens, Wenger, Kreling, & Connors, 1997). As the terminally ill, elderly cancer patient proceeds through his/her illness trajectory, the decline in functional and self-care abilities will impact the degree to which the caregiver will be needed to manage the patient's symptoms. The addition of chemotherapy or radiation therapy brings with it fatigue, nausea, vomiting, dry mouth, and poor appetite. Many individuals with cancer experience pain due to the burden imposed by the size of the tumor or due to metastasis of the cancer to other sites, such as liver or bone. If comfort measures, such as pain control, are the only treatment options, then the addition of narcotic analgesia to promote comfort may cause the patient to experience drowsiness and/or an altered sensorium, further

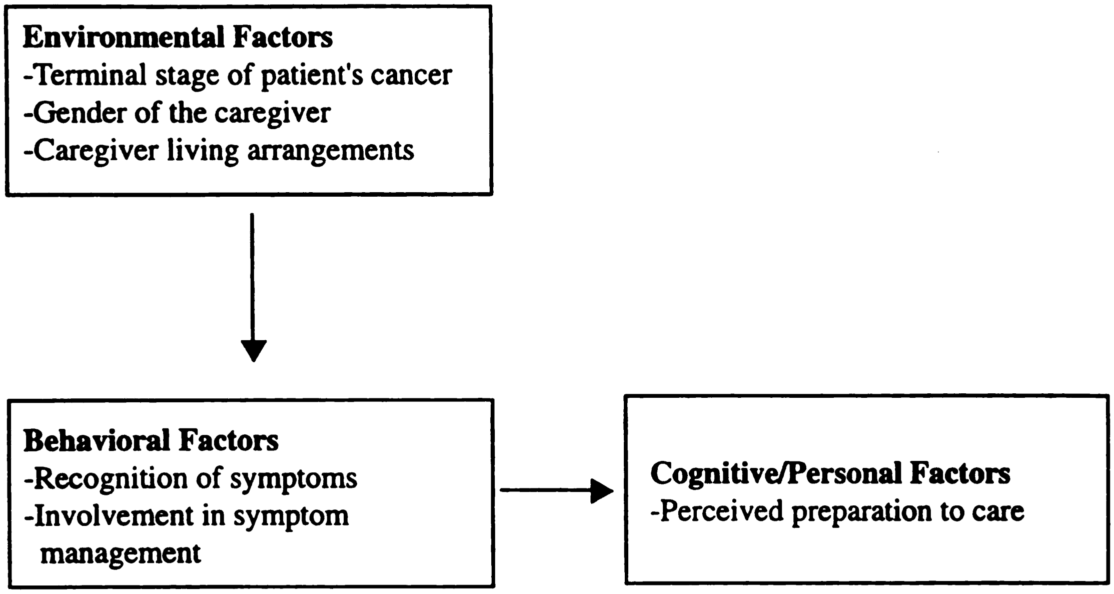

Figure 2. A Modification of the Bandura Model (1986), Depicting Environmental Factors' Impact on Behavioral Factors, and Behavioral Factors' Impact on Personal Factors.

limiting the patient's capacity to participate in self-care measures to alleviate other manifesting symptoms.

The Caregiver Symptom Assistance categories include: nausea, pain, trouble sleeping, fatigue, difficulty breathing/shortness of breath, diarrhea, coordination problems, vomiting, poor appetite, weight loss, fever, cough, dry mouth, constipation, and frequent urination.

Caregiver Preparation to Care categories include prepared to: Care for the patient's physical needs; care for the patient's emotional needs; find out about and set-up physical needs; care for the patient's emotional needs; find out about and set-up formal services for the patient's care; care for the patient's medical/nursing treatments; manage bills, finances, and insurance forms related to the patient's care needs; plan for the patient's activities; manage the patient's behavioral problems; manage equipment and techniques necessary to care for the patient; help in managing the patient's symptoms; discuss with health care providers the problems the patient is having; help the patient get cancer treatments; find the information the caregiver needs about cancer; and overall for the role of caregiving.

The sociodemographic variables (environmental factors) for the caregivers in this study include caregiver gender and caregiver living arrangements. These variables are believed to impact the caregivers' perceived preparation to care. Living arrangements will facilitate caregivers' recognition of symptoms experienced by their patients', and impact the levels of involvement of the caregivers in the management of their patients' symptoms. Caregiver gender may further impact the caregiver's perceived preparation to care, as females tend to be socialized into nurturing roles more than males.

The sociodemographic variables for the patients (also environmental factors) in this study include age, and terminal staging of cancer. These variables are also believed to impact the caregivers' levels of involvement in the management of their patients' symptoms, as well as the caregivers' perceived preparation to care.

Review of Literature

Research literature involving caregivers involved in symptom management for their cancer patients is limited. Much of the research surrounding caregiver activities for cancer patients involves assistance with Activities of Daily Living or Instrumental care tasks. Caregiver preparedness is a unique concept, and has been addressed by a select few researchers.

Symptom Experiences with Terminal Cancer and Other Terminal Illnesses

Pereira, Hanson, and Bruera (1997) administered Mini Mental State Examinations (MMSE) to 321 terminally ill cancer patients who were admitted to a palliative care unit over a 26 months time span. Each patient was tested at the time of admission, and thereafter an average of 4.7 times, occurring every 4.9 days. The cancer sites under study included: gastrointestinal (n=86), genitourinary (n=75), lung (n=68), breast (n=44), head and neck (n=16), unknown (n=11), other (n=11), hematologic (n=9), and sarcoma (n=1). The mean age of the patients under study was 64.2 years. Two hundred and thirty-one of the patients died during admission and 90 patients were discharged. One hundred and forty-two patients had abnormal MMSE scores on admission, 176 patients had abnormal MMSE scores at the time of either death or discharge. Of the 240 patients who were tested two or more times, 99 patients had normal initial and final MMSE scores, 54 had normal initial but abnormal final scores, and 62 had abnormal initial and final scores. When abnormalities were discovered, diagnostics were conducted to assess for the presence of opioid toxicity, infection, dehydration, brain metastases, uremia, renal failure, hypercalcemia, sepsis, and hypoxia. Also, complete medication reviews were conducted. Corrective measures, such as medication adjustment/discontinuation or rehydration, were undertaken when probable cause(s) could be determined.

Kurtz, Kurtz, Given and Given (1996) studied a sample of 216 patient-caregiver dyads to determine the level of concordance between cancer patient and caregiver reported symptoms. The cancer sites included were breast, lung, colo-rectal, lymphoma, gastrointestinal, prostate, gynecologic, and other. The top five caregiver reported symptoms were (in descending order): fatigue, insomnia, loss of appetite, pain, and nausea. Site and stage of cancer will influence not only the type of symptom experienced, but also the magnitude of the symptom experience. The overall accuracy of caregiver versus patient symptom reports was 71%.

Ferrell, Taylor, Grant, Fowler, and Corbisiero (1993) reported that two-thirds of all patients with advanced cancer experience significant pain. They studied ten patient-caregiver-nurse triads to ascertain special problems associated with pain management, identified by the patients, caregivers, and the home care nurses. The cancer diagnoses under study were prostate (n=3), lung (n=2), breast (n=1), colon (n=1), myeloma (n=1), thyroid (n=1), and vulvar (n=1). The caregivers identified a sense of futility in managing the patients' pain and an awareness of impending death. The sense of futility was most frequently attributed to ignorance and a lack of trained support.

Pickett, Cooley, Patterson, and McCorkle (1996) studied 65 post radical retropubic prostatectomy cancer patients, to outline how these patients could experience improved quality of life from the utilization of comprehensive home care services. The patient (n=65) reported symptoms included incontinence (100%), cough (89%), pain intensity (74%), nausea frequency (66%), changes in breathing (65%), poor outlook (62%), nausea intensity (59%), pain frequency (55%), changes in appearance (48%), lack of concentration (40%), fatigue (34%), changes in appetite (28%), inability to sleep (23%), and bowel changes (11%).

Sarna and McCorkle (1996) described the symptom experiences of lung cancer patients, citing changes in mental status, pain, fatigue, dyspnea, weight loss, anorexia, and cachexia in progressive disease. Further, these patients report an almost constant requirement of care, diminished quality of life, and decline in their physical health.

Hinton (1994) examined the experiences of 77 terminally ill cancer patients, with a mean age of 65 years, and their caregivers in the United Kingdom. The patients identified pain, weakness, nausea/vomiting, malaise/fever, constipation, dyspnea, anorexia, immobility, cough, diarrhea, edema, ulcer/discharge, dysphagia, and incontinence as symptoms that some, but not all of them, had experienced. Cancer diagnoses included: lung (n=18), stomach (n=11), bowel/rectum (n=11), breast (n=9), and other (n=28). The caregivers identified pain, weakness, dyspnea, diarrhea, and dysphagia as causing peak distress for them.

Lynn and colleagues (1997) studied 3357 terminally ill patients, with a mean age of 66.6 years, who had surrogate decision makers in order to better understand the experience of dying. The patients carried diagnoses of acute respiratory failure, multiple organ system failure, chronic obstructive pulmonary disease, congestive heart failure, cirrhosis, coma, colon cancer, or lung cancer. Of the patients who were conscious prior to death, 40% had severe pain, more than 50% experienced severe dyspnea in the last three days of life, severe confusion was experienced by nearly 25%, less than 13% experienced severe nausea, and 80% suffered from severe fatigue. The surrogates reported that

73% of the patients experienced great difficulty in tolerating these symptoms.

The literature reviewed offered consistent views of the symptom experiences of patients with terminal cancers or other terminal illnesses. Cognitive deficits (Pereira, Hanson, & Bruera, 1997), pain (Ferrell, Taylor, Grant, & Corbisiero, 1993; Sarna, & McCorkle, 1996; Kurtz, Kurtz, Given, & Given, 1996; Lynn and colleagues, 1997), fatigue, nausea, loss of appetite (Sarna, & McCorkle, 1996; Kurtz, Kurtz, Given, & Given, 1996; Hinton, 1994) are but a few of the symptoms with which terminally ill cancer patients and their caregivers must contend. Kurtz, Kurtz, Given, and Given (1996) introduced the caregiver as proxy for reporting the patient's symptoms, providing a different avenue for assessing not only efficacious but also deleterious effects of both active and palliative treatment modalities for cancer.

Caregiver Involvement in Symptom Management

Stetz (1987) examined the caregiver demands from 65 terminally ill cancer patients. Sites of cancer were: lung (n=20), prostate (n=11), breast (n=7), with the remainder of the sites not listed; the authors reported each unnamed site had fewer than seven subjects per category. Sixty-nine percent of the caregivers reported they were managing the imposed changes within the patients, such as coping with alterations in the physical and/or emotional state of the ill patient.

Schumacher (1996) investigated the acquisition of the caregiver role in 19 caregivers for patients with gastrointestinal, lung, genito-urinary, breast, or gynecological cancer, or lymphoma. Care tasks were organized into twelve domains, one being symptom management. Care delivery was divided into three patterns: self-care, caregiving, and collaborative. This recognizes that patients' abilities to manage their symptoms run along a continuum from total self-care to total dependency. Caregivers described their experiences within this care continuum, from performing all aspects of symptom management, to discussing presence of symptoms with the patients and collaboratively deciding how to best alleviate the manifested symptom. She further described a phenomenon termed task specialization, where some care tasks are carried out solely by one member of the dyad and other care tasks are carried out by the other member of the dyad, based on expertise.

Given and Given (1994) described the family caregiver's involvement in symptom management varies, and includes direct care, complex monitoring and decision making, and emotional support. Further, the symptom distress experienced by the patient varies according to numbers of symptoms, severity of the experience, and frequency of the occurrence. This variance will determine not only the type of involvement, but also the level of involvement required from the family caregiver.

Given and Given (1994) discussed the management strategies utilized by caregivers to alleviate pain in their patients. Determining the source, nature, and amount of pain, then utilizing pharmacologic and non-pharmacologic methods, such as positioning, distraction, emotional support, and applying heat, cold, or lotions to the site. Other symptoms that often require management by the caregiver include nausea, loss of appetite, and fatigue. When symptoms occurred in groups, or constellations, they often overwhelmed the caregiver and impeded his/her ability to effect any positive change in them.

Caregiver involvement in the management of cancer and treatment related symptoms can be intense and overwhelming. Caregivers are providing direct care and monitoring for efficacy of their efforts (Stetz, 1987; Given, & Given, 1994), some of the symptom management tasks are `delegated' based on a continuum of the patient's capacity to perform self-care and/or based on the idea of task specialization (Schumacher, 1996). Caregivers experience greater challenges when symptoms occur in clusters (Given, & Given, 1994), which can overwhelm the caregiver. These authors did not incorporate the concept preparedness in their studies.

Perceived Preparation to Care and its Impact on Caregiving

Rusniak and Murphy (1995) examined 30 caregivers for their spouses, who had been recently diagnosed with cancer, to determine the relationship between the caregivers' knowledge of cancer care and their perceived preparedness for the caregiving role. The caregivers ranged in age from 65 years to 84 years ($\underline{x}=71.7$). The patients ranged in age from 65 years to 87 years ($\underline{x}=74.1$). Eighty-three percent of the caregivers were female. The average length of time elapsed since the initiation of caregiving was 4.1 months. The caregivers reported a moderate level of perceived preparedness to care. Of interest, level of caregiver specific education was negatively correlated with perceived preparedness to care ($r=-.37$; $p=.02$).

Archbold, Stewart, Greenlick, and Harvath (1990) gathered data from 78 patient-caregiver dyads to examine the impact that mutuality and preparedness have on caregiver role strain. The care recipients ranged in age from 65 to 93 years of age. The caregivers were predominantly female (62%), with 19% being the wife of the care recipient. The aspects of role strain, strain from direct care, increased tension, and global strain, appeared lower when higher levels of perceived preparedness were reported by the caregivers. The authors did not address the types of care that were being provided by the caregivers in their sample.

Archbold, Stewart, Miller, Harvath, Greenlick, Van Buren, Kirschling, Valanis, Brody, Schook, and Hagan (1995) studied 22 patient-caregiver dyads, with 11 assigned to each group, control versus experimental, to pilot a system of home health nursing interventions, PREP (PReparedness, Enrichment, Predictability), designed to increase the preparedness and competence of family caregivers, as well as to enrich the process of caregiving. In analyzing the data, there were no significant differences between the experimental and control groups on the strain measures, rewards of caregiving, or two depression scales. But, caregivers in the group that received the PREP intervention experienced enhanced preparedness, enrichment, and predictability in the caregiving process. The authors in this article did not address specific caregiving tasks that were being performed.

Caregiver preparedness was an elusive topic in the research literature. The literature that was devoted to preparedness, discussed the relationships between caregiver perceived preparedness to care and psychosocial outcomes for the caregiver, such as role stain, depression, predictability, and enrichment. Rusniak and Murphy (1995) found that caregiver-specific education and caregiver perceived preparedness to care were negatively correlated, whereas Archbold, Stewart, Miller, Harvath, Greenlick, Van Buren, Kirschling, Valanis, Brody, Schook, and Hagan (1995) found that caregivers who were exposed to the PREP intervention experienced enhanced preparedness to care.

Caregiver Gender

Societal expectations of who shall assume the role of caregiver tends to fall onto women, as women are socialized to be nurturing and the caring, thus caregiving is felt to be an extension of the normal female role (Allen, 1994). Rusniak and Murphy (1995) found that 83% of their caregiver sample were women, and Archbold, Stewart, Greenlick, and Harvath (1990) finding that 62% of their sample were women. Allen (1994) investigated the gender differences in spousal caregiving in a sample of 353 married individuals with cancer who were receiving outpatient treatment. The sample of caregivers included 188 (53%) female spousal caregivers and 165 (47%) male spousal caregivers. The female patients (*n*=165) reported a mean of 2.2 (*SD*=1.3) symptoms and the male patients (*n*=188) reported a mean of 2.1 (*SD*=1.3) symptoms. Male patients received more assistance (45%) with personal care (which included involvement in symptom management) from their spouses than did female patients, where 30% received assistance with personal care.

Caregiver Living Arrangement

Tennstedt, Sullivan, McKinlay, and D'Agostino (1990) studied 429 informal caregivers for frail elders to determine use of community-based formal services. Seventy-nine percent (340) of the patients received most of their help from their informal caregivers. The authors determined that those patients who lived alone relied more on formal services, and that elders who co-resided with a caregiver, particularly a spousal caregiver, were more apt to not utilize formal services, regardless of their levels of frailty.

Tennstedt, Crawford, and McKinlay (1993) examined 445 patient-caregiver dyads to determine if co-residence of a frail elder with a caregiver resulted in a kinship primary group similar to a marital bond. They examined types and amounts of both informal and formal care delivery and found that co-residing caregivers had higher rates of informal care provision than non-co-residing caregivers, regardless of the patients' relationship to them.

Patients who co-reside with their caregivers are more apt to utilize only the informal services provided to them through their co-residing caregivers, regardless of levels of frailty. Although these articles did not specifically address the caregivers' levels of involvement in symptom management, they did address levels of involvement in personal care (authors' terminology), beyond Activities of Daily Living and Instrumental care tasks.

The most consistent findings within the research literature surrounded the symptom experiences of terminally ill cancer patients and the symptom involvement of the caregivers. Caregiver perceived preparedness was not found to exist consistently within the cancer care research. This inconsistency could be attributed to the unique traits inherent within each caregiver that are molded through life experiences, such as personality, self-esteem/self-concept, and knowledge base.

The literature reviewed provides some support for the conceptualization of this study. The environmental factors (co-residency, caregiver gender) tend to drive the behavioral factors (involvement in personal care) for the caregivers that were studied. The one aspect of the model that was not addressed completely in the literature was how the environmental factors and behavioral factors impacted the caregivers' personal/cognitive factors (perceived preparedness to care).

Methods

Research Design

These data are from a sub-sample taken from the larger study, Family Home Care for Cancer--A Community-Based Model, Grant #2 R01 NR/CA01915, funded by the National Institute for Nursing Research and the National Cancer Institute, Barbara A. Given, PhD, RN, FAAN, and Charles W. Given, PhD, Principal Investigators.

The original study was an inception cohort of elderly patients with cancer and their caregivers. This longitudinal study was a collaborative effort between Michigan State University (MSU) College of Nursing; MSU College of Human Medicine, Department of Family Practice; the Cancer Center at MSU; and the MSU Cancer Treatment Consortium.

Study Sample

The patients and caregivers were accrued into the original study via convenience sampling from 30 sites, including hospitals, physicians' offices, and community cancer treatment settings where the patients sought treatment for their newly diagnosed cancers. These settings were located in various Michigan cities, including Lansing, Grand Rapids, Kalamazoo, Saginaw, Flint, and St. Joseph, as well a site in Indianapolis, Indiana. Eligibility criteria for the patient included the following conditions: The patient had to be 65 years of age or older; newly diagnosed with lung, colorectal, breast, or prostate cancer; currently undergoing some form of treatment beyond palliation; and the patient could not have received treatment within the previous three years for another cancer. The patients included in this sub-sample all died after the Wave 2 interview (conducted at twelve weeks after entry into the study) but prior to the Wave 3 interview (conducted at twenty-four weeks after entry into the study).

In order for a caregiver to be eligible for participation, he/she had to be identified by the patient as the primary person who was involved in his/her home care, and the identified caregiver had to be available to provide care to the patient over the next 12 months. This caregiver could be a family member (spouse, child, sibling, niece/nephew), or an unrelated significant other (neighbor, friend, fellow church member). The identified caregiver could participate in the study with or without the patient's participation.

The sub-sample for this study consists of 41 caregivers for patients with cancer. The eligibility for entry into this secondary analysis included: Family or unrelated significant other caregivers for elderly patients who were newly diagnosed with lung, colorectal, breast, or prostate cancer who died prior to completing the larger longitudinal study.

A search was performed on the data base to identify all patients who had died and who had an identified caregiver participating in the study. Another query was performed, seeking the last telephone interview that was completed by each caregiver prior to the patients' deaths.

Data Collection Procedures

Data collection for the larger, longitudinal study began with an initial screening by a trained nurse recruiter. Within two-weeks following identification and consent, both patient and caregiver were contacted via telephone, by a trained interviewer, to establish a day and time to complete the first wave interview. Each telephone interview required 45 minutes to one hour of each participant's time. The patient and caregiver were interviewed separately, and each interview consisted of structured, closed-ended questions. These interviews occurred post-operatively and within two weeks of the time that the patient received chemotherapy or radiation. In addition to the telephone interview, a Self-Administered Booklet (SAB) was mailed to each participant, to be completed and returned. Subsequent data collection, interview and SAB, occurred at 12, 24, and 52 weeks, as well as medical records audits.

The interviewers were health professionals students. Interviewer training consisted of: a) mock interviews, b) taped interviews, c) monthly interviewer meetings during the data collection period, d) monthly quality assurance completed on 10% of each interviewer's case records, and e) monthly quality assurance of interviewing technique, via submitted taped interview, to ensure that the protocols of the research study were being adhered to. Each interviewer was provided with an interviewer manual that provided explicit instructions/information regarding the aims, protocols, and policies of the research study.

For this secondary analysis, only the caregiver was utilized as the source of data. The date of death for each patient was recorded in the data management system, and from this date, the last wave interview and SAB completed by the caregiver, prior to the patient's death, were utilized to obtain the necessary data. The questions utilized from the telephone interview queried the caregiver about the patient's symptom experience and whether or not the caregiver provided any assistance to the patient in response to the symptom. The questions utilized from the SAB queried the caregiver about his/her perceived preparation to care for the patient.

Operational Definitions

The independent variables in this study were: 1) the number of patient symptoms reported by the caregiver within the previous two-weeks; 2) the number of patient symptoms the caregiver was involved in managing within the previous two-weeks; and 3) the proportion of the symptoms the caregiver was involved in managing. This information was gleaned from the Activities of Symptom Management Assistance.

The caregivers were asked to respond to queries regarding the presence of symptoms, within the previous two-weeks, in the patients. The Activities of Symptom Management Assistance questions consisted of 15 symptoms: nausea, pain, trouble sleeping, fatigue, difficulty breathing/shortness of breath, diarrhea, coordination problems, vomiting, poor appetite, weight loss, fever, cough, dry mouth, constipation, and frequent urination. If the caregiver responded affirmatively to a symptom, then further query was performed to ascertain if the caregiver provided any assistance to the patient in response to the symptom.

The dependent variable in this study was caregiver perceived preparation to care. Caregiver perceived preparedness to care is defined as how well prepared a caregiver feels to perform a set of caregiving tasks from the Caregiving Preparedness category. The data for the dependent variable were gathered from the completed SAB.

The Caregiver Preparedness category consists of queries to caregivers regarding 12 tasks of care, including caring for the patient's physical needs; caring for the patient's emotional needs; finding out about and setting up formal services for the patient; caring for medical/nursing treatments for the patient; managing finances, bills, and insurance forms for the patient; planning for activities for the patient; managing equipment and techniques for the patient; helping in the management of the patient's symptoms; discussing with the patient's doctors any problems the patient is having; helping the patient get to cancer treatments; and finding the information the caregiver needs about cancer. These questions ask the caregiver to consider how well prepared he/she perceives him/her self in carrying out these tasks. The Caregiver Preparedness category also consists of one question which asks the caregiver to consider his/her preparation for being a caregiver in general.

The sociodemographic characteristics of the patient include: 1) age, 2) site of cancer, and 3) terminal stage of cancer. Patient age was measured in years. Patient site of cancer includes: 1) lung, 2) colorectal, 3) breast, and 4) prostate. Patient terminal stage includes those who deceased within six months of beginning the study.

The sociodemographic characteristics of the caregiver includes: 1) gender, and 2) living arrangement. Caregiver gender includes: 1) female, and 2) male. Caregiver living arrangements includes: 1) lives with the patient, and 2) does not live with the patient.

Measurement and Scoring

The larger study, Family Home Care for Cancer--A Community-Based Model, utilized two scales to collect data from the caregivers regarding their involvement in assistance with managing symptoms (see Appendix A) and their perceived preparation to care (see Appendix B).

The Caregiver Symptom Assistance categories were ascertained by querying the caregiver regarding whether or not the patient either had or complained of a listing of 15 illness and treatment related symptoms, with responses being (1) yes, or (2) no. If the caregiver responds affirmatively to any symptom, then the caregiver is asked whether or not assistance to the patient was rendered in response to that symptom, with responses being (1) yes, or (2) no. The Caregiver Symptom Involvement scale did not have a calculated Cronbach's alpha from its use in the original longitudinal study. It appears to be a valid measure and has been utilized extensively in research studies. The caregiver proxy of the patient's symptom experience summated scale ranged from 0-15. The Caregiver Symptom Assistance summated scale ranged from 0-15.

Preparedness categories were ascertained through the SAB by querying the caregiver regarding how well prepared he/she felt in performing twelve different aspects of the caregiving role and one global assessment of the total caregiving role. The responses were on a four-point Likert scale: 1) not at all prepared, 2) not too well prepared, 3) pretty well prepared, or 4) very well prepared. Cronbach's alpha for the Preparedness scale is .85. The Preparedness summated scale ranged from 13-52.

Data Analysis

Research Question 1 seeks to determine which aspect of symptom involvement predicts caregiver perceived preparation to care, the number of patient symptoms reported by caregiver proxy, the number of symptoms that the caregiver is involved in managing, or the proportion of the symptoms experienced by the patient that the caregiver is involved in managing. This question will be answered utilizing multiple linear regression techniques.

First, a Pearson Product Moment correlation will be performed to examine correlations among all three independent variables. If all three bivariate correlations are less than .60, then each independent variable will be entered step-wise into the regression equation, with the number of caregiver reported symptoms entered first, to see how it predicts the dependent variable. If the three bivariate correlations are greater than .60, then each independent variable must be entered separate, because any large inter-correlations between the independent variables can substantially affect the results of the multiple regression analysis. Next, the number of symptoms the caregiver was involved in managing will be added to the regression to see if its addition accounts for additional variance within the dependent variable. Finally, the proportion of symptoms the caregiver was involved in managing to the number of symptoms the caregiver reported the patient experienced will be added to the regression to determine if this addition accounts for further variance within the dependent variable.

Once these regressions are completed, the addition of caregiver characteristics, relationship to the patient and living arrangements, will be added as co-variates, to determine if these further impact the dependent variable.

Protection of Human Subjects

In the larger study, Family Home Care for Cancer--A Community-Based Model, Grant #2 R01 NR/CA01915 patients were initially approached, by a project staff member, while hospitalized, to introduce the study, discuss the process (interviews and SABs), and inquire if they were interested in participating. Each hospital from where patients were recruited agreed to allow the project staff members to recruit their patients, and the Oncologists were also appraised of the research study and its aims.

Patients were asked to identify a primary caregiver, who would be willing to assist them with care needs throughout the following year. Caregivers could participate in the larger longitudinal study with or without the patient participating. Patients and caregivers who agreed to participate signed a consent form (see Appendix B). Participants had the following rights: 1) to withdraw from the study at any time; 2) to ask questions about their role in the research study; and 3) to refuse to answer any questions posed to them.

Anonymity and confidentiality of all research participants were protected by the researchers via assigning case numbers to each participant. All instruments were labeled using the case identification number. The data could not be linked to any of the participants individually. The signed consent forms are on file within the Family Care Studies department and are accessible only to the Principal Investigators. The original study, Family Home Care for Cancer--A Community-Based Model, Grant #2 R01 NR/CA01915, was approved by the University Committee on Research Involving Human Subjects (UCRIHS) at Michigan State University (see Appendix C). This UCRIHS approval is reviewed on a yearly basis while the data collection is in progress.

Approval to conduct the secondary analysis was sought by this researcher, and approved by UCRIHS prior to initiation of the data analysis (see Appendix D). A sub-sample from the original longitudinal study is being utilized for this secondary analysis. As previously reported, all necessary consent forms are signed and currently on file. Data for this secondary analysis will be taken from the last wave, caregiver interview that was conducted prior to the patient's death. The data provided for this secondary analysis will not contain any participant identifiers. There are no anticipated risks to any of the participants from the conduction of this secondary analysis;

the data have already been collected and no further participant contact will be required.

The results of this research will not be explained to the participants unless they request such explanation. In the event that the results from this secondary analysis are published, analyses may not identify any individuals, however, references to the cohort as a whole are permissible.

Research Limitations

The original study utilized convenience sampling to acquire its study participants. Self-selection into research may impose extraneous characteristics that while not part of the study, may influence the analyses due to influence of or relatedness to the variables of interest. This self-selection imposes a threat to this study's internal validity.

The lack of random sampling within the original study and the small sample size for the secondary analysis imposes a threat to this study's external validity, as well as limits the extent to which the results can be generalized to the population.

Co-morbid health conditions will impact patients' symptom experiences. These conditions, although queried for in the original study, are not being examined within this secondary analysis and they impose a threat to the study's internal validity.

Previous cancer caregiving experience was not queried in the original study. Previous experience in cancer caregiving will impact the level of perceived preparedness to care for a caregiver and is imposes a threat to the study's internal validity.

The small sample size (n=41) utilized for this study greatly hinders the study's ability to be generalized to the larger target population. This limitation introduces a threat to the study's external validity, however, it can serve as an exploratory study to examine patterns of caregiver symptom involvement and to generate other research questions.

Results

Description of the Sample

The sample consisted of 41 caregivers; with four (11.4%) of the caregivers in the 40-49 years age range, five (14.3%) of the caregivers in the 50-59 years age range, fifteen (42.9%) of the caregivers in the 60-69 years age range, and eleven (31.4%) of the caregivers in the 70 years and older age range. There were six cases in which the caregiver age was not available.

Thirty-five (85.4%) of the caregivers were female and six (14.6%) were male. Thirty-four (82.9%) of the caregivers lived with their patients and seven (17.1%) of the caregivers resided in a domicile other than that of their patient (see Table 1).

Table 1.

Frequencies and Percentages of Sample Demographic Characteristics n=41

Demographic Characteristics	n	%
Caregiver Age		
40-49 years	4	11.4
50-59 years	5	14.3
60-69 years	15	42.9
70 years and above	11	31.4
* missing values	6	
Caregiver Gender		
Female	35	85.4
Male	6	14.6
Caregiver Lives with Patient		
Yes	34	82.9
No	7	17.1
Caregiver Relationship to Patient		
Spouse	28	75.7
Non-spouse	9	24.3
* missing values	4	
Patient Age		
65-74 years	24	58.5
75 years and above	17	41.5
Patient Gender		
Female	14	34.1
Male	27	65.9
Patient Diagnosis		
Breast	1	2.4
Colon	5	12.2
Lung	31	75.6
Prostate	4	9.8

The patients for whom this sample of caregivers rendered care were at least 65 years old. Twenty-four (58.5%) of the patients were in the 65-74 years age range and seventeen (41.5%) of the patients were in the 75 years and older age range.

Fourteen (34.1%) of the patients were female and 27 (65.9%) of the patients were male. The patients within this sample had cancer diagnoses of breast (n=1, 2.4%), colon (n=5, 12.2%), lung (n=31, 75.6%), or prostate (n=4, 9.8%) (see Table 1).

Answers to Research Questions

1. During the period of time prior to the patient's death, is it the number of symptoms the caregiver reported that the patient experienced, the number of symptoms that the caregiver was involved in managing, or the proportion of symptoms experienced by the patient that the caregiver was involved in managing that predicts caregiver perceived preparedness?

During the interview wave prior to death, caregivers (n=36) reported that patients experienced a mean of six symptoms (SD = 2.90) (see Table 2). Caregiver recognition of the patient's symptom experience was not statistically significant (F=.01, p=0.915) in predicting caregiver perceived preparedness. Caregivers (n=36) reported assisting in managing a mean of 2.27 patients' symptoms (SD= 2.34) (see Table 2). Global perceived preparedness to care was reported at a mean of 3.07 (SD=.49) by the 32 caregivers who responded in the SAB portion of the data collection. Caregiver assistance in managing patient's symptoms was not statistically significant (F=0.56, p=0.460) in predicting

Table 2

Regression Analysis of Independent Variables and the Impact on the Dependent Variable

Independent Variable			Impact on Preparedness		
	n	*M*	*SD*	F	*p*
Symptom Recognition	36	6.00	2.90	0.01	0.92
Symptom Assistance	36	2.27	2.34	0.56	0.46
Proportion Assistance		0.44	0.27	0.40	0.54

caregiver perceived preparedness to care. The proportion of symptoms experienced by the patient that the caregiver was involved in managing ranged from .09-1.0 (*M*=.44, *SD*=.27) at the interview wave prior to death (see Table 2). The proportion of symptoms experienced by the patient that the caregiver was involved in managing was not statistically significant (F=.397, *p*=0.535) in predicting caregiver perceived preparedness to care.

Thus, the number of symptoms that the caregiver reported that the patient experienced, the number of symptoms that the caregiver was involved in managing, and the proportion of the symptoms experienced by the patient that the caregiver was involved in managing were not found to be predictive of levels of perceived preparedness to care in caregivers for elderly, terminally ill cancer patients within this subsample.

2. How does the caregiver's gender and living arrangements further impact the caregiver's perceived preparedness?

Female caregivers (n=30) reported mean preparedness scores of 2.9 (SD=0.7), and male caregivers (n=4) reported mean preparedness scores of 2.7 (SD=0.5). Caregiver gender was not statistically significant (F=.01, p=0.967) in predicting caregiver perceived preparedness to care (see Table 3).

Caregivers who reside with the patient (n=31) reported mean preparedness scores of 2.9 (SD=0.6). Caregivers who resided in domiciles other than that of the patient reported mean preparedness scores of 2.3 (SD=0.3). Caregiver living arrangements was not statistically significant (F=.33, p=0.572) in predicting caregiver perceived preparedness to care (see Table 3).

Thus, in response to the second research question, how does caregiver gender and living arrangements further impact the caregiver's perceived preparedness, it was found that neither caregiver gender nor living status were found to be predictive of caregiver perceived preparedness to care for elderly, terminally ill cancer patients within this sub-sample.

Within the Caregiver Symptom Involvement questions, from the interview, there were five cases in which responses were missing from the interview. Because of this, these five cases were not included in the data analysis, and they were excluded from the linear regression equation. Likewise, within the Caregiver Preparedness questions, from the SAB, there were seven cases that either did not respond to these questions, or did not return their SAB. Because of this, these seven cases were not included in the data analysis, and they were excluded from the linear regression equation.

Other Findings

The lack of statistical significance of the impact that the independent variables had on the dependent variable brought about further querying of the data. Of interest, was the unmet need that was apparent in the patients. For the purposes of this research, unmet need is being defined as any caregiver identified symptom experienced by the patient that the caregiver does not involve him/her self in managing. Although 30 caregivers (n=36) reported that their patients were experiencing fatigue at the wave prior to death, only seven of those 30 caregivers were involved in assisting their patient in managing the fatigue (see Table 4). In examining the top six caregiver recognized patient symptoms and top six symptoms in which caregivers were involved in managing, the unmet need that terminally ill, elderly cancer patients were experiencing within this sample was quite large (see Tables 4 and 5).

Despite the relatively high perceived preparedness scores that this sub-sample of caregivers (*n*=34) reported, specific to symptom management care tasks (see Table 6), there remained a considerable amount of unmet needs within their patients. Sixty-seven percent (*n*=23) of the caregivers reported "feeling pretty well prepared" or "very

Table 3.

Caregiver Gender and Living Status Mean and Standard Deviation of Preparedness and the Impact on Perceived Preparedness

Variable	Perceived Preparedness				Impact	
	n	%	M	SD	F	p
Caregiver Gender					.01	0.97
Female	30	88	2.9	0.7		
Male	4	12	2.7	0.5		
Living Status					.33	0.57
Together	31	91	2.9	0.6		
Apart	3	9	2.3	0.3		

Table 4.

Top six Caregiver Reported and Assisted Symptoms in Patients Prior to Death (n=36)

Caregiver Reported	n	%	Caregiver Assisted	n	%
Fatigue	30	83	Pain	12	57
Pain	21	58	Poor Appetite	11	69
Cough	20	56	Nausea	9	56
Dyspnea	17	47	Fatigue	7	23
Nausea	16	44	Constipation	6	60
Poor Appetite	16	44	Dry Mouth	5	38

Table 5.

Top six Caregiver Reported Symptoms and Unmet Need at the Wave Prior to Death (n=36)

Symptom Reported (n=36)	n	%	Unmet Need (n=36)	n	%
Fatigue	30	83	Fatigue	23	77
Pain	21	58	Pain	9	43
Cough	20	56	Cough	17	85
Dyspnea	17	47	Dyspnea	14	82
Nausea	16	44	Nausea	7	44
Poor Appetite	16	44	Poor Appetite	5	31

Table 6.

Level of Perceived Symptom Management Preparedness, Frequency and Percent (n=34)

Level of Preparedness	f	%
Not at all prepared	3	8.8
Not too well prepared	8	23.5
Pretty well prepared	19	55.9
Very well prepared	4	11.8

well prepared" to assist their patients in managing symptoms. It may be possible that perceived preparedness is not the issue for this sample, rather recognition of need to assist, or perhaps having the knowledge base to know when and how to assist, may be the issues. If these caregivers do not attribute symptom management to the domain of caregiver role asks, then the great amounts of unmet need seen within this sub-sample of patients may not cause these caregivers to feel less prepared to provide care to their patient. These caregivers may believe that symptom management lies within the domain of the formal health care system.

Another plausible explanation for these results is that caregivers may not believe that there is anything that can be done to alleviate the symptoms experienced by their patients, especially in light of the terminal phase of the cancer disease. Or, it may be possible that the symptoms present in such a vague manner that the caregiver feels unable to manage them. For a caregiver with this mind set, perceived preparedness will not be impacted, because if he/she believes that nothing can be done to alleviate a symptom, then he/she may not feel that his/her lack of attending to this need necessarily deems him/her less prepared to care.

In examining the unmet need, patient diagnosis site, and caregiver characteristics another interesting finding was discovered: Caregivers who do not live with their patients are involved to a greater degree in managing their patients' symptoms than caregivers who reside within the same domicile as their patients, thus these patients have less unmet need than patients whose caregiver resides with them (see Table 7). Some of the possible explanations for this difference in symptom involvement include: Caregivers who live apart from their patients assist with more symptom

Table 7.

Caregiver Demographic Characteristics and the Mean and Standard Deviation of Caregiver Reported Symptoms and Assisted Symptoms, and Patient Unmet Needs

Caregiver Characteristics	Reported Symptoms			Assisted with Symptoms		Patient Unmet Needs	
	n	M	SD	M	SD	M	SD
Spouse							
Female	24	6.0	3.5	2.1	2.6	4.0	2.9
Male	4	6.5	3.5	2.3	2.9	4.3	1.9
Non-Spouse							
Female	8	8.3	3.7	4.3	2.5	4.0	4.0
Male	1	3.0		0.0		3.0	
Living Status							
Together	32	6.5	3.7	2.0	2.5	4.5	3.2
Apart	7	6.7	2.9	4.4	2.5	2.3	1.6
Patient Cancer Site							
Breast, Colon, or Prostate	10	5.3	3.5	2.3	2.7	3.0	2.4
Lung	29	7.0	3.5	2.5	2.7	4.4	3.2

management tasks because they attribute symptom management to the domain of the caregiver role; Caregivers who live apart from their patients are goal directed in their caregiving activities due to other role obligations, such as family, social, civic, and/or employment obligations; Care provided by caregivers who live apart from their patients may seem more like deliberate care, whereas care provided by caregivers who live with their patients may seem more natural, as an extension of their relationship and usual function. Patients in this sub-sample, who were diagnosed with lung cancer, on average, experienced more symptoms and had greater amounts of unmet need than patients who were diagnosed with breast, colon, or prostate cancer (see Table 7).

Female spousal and male spousal caregivers provided nearly the same amounts of symptom assistance as female non-spousal caregivers, and the one male non-spousal case in this sub-sample did not involve himself in symptom management (see Table 7).

Discussion

Sample

In this descriptive study, 41 caregivers for elderly, terminally ill cancer patients were queried to determine the level of their symptom recognition and involvement in managing their patient's symptoms. These results were utilized to examine how the level of the caregivers' symptom recognition and involvement in managing their patients' symptoms impacted the caregivers' perceived preparedness to care. Then further inquiry was conducted to investigate whether caregiver gender or living arrangements further impacted the caregivers' perceived preparedness to care.

Four (11.4%) of the caregivers in this sub-sample were 40 to 49 years old, five (14.3%) of the caregivers were 50-59 years old, fifteen (42.9%) of the caregivers were 60-69 years old, and eleven (31.4%) of the caregivers were 70 years old or older. Thirty-five (85.4%) of the caregivers in this sub-sample were female, and six (14.6%) were male. Thirty-four (82.9%) of the caregivers lived with their patient and 7 (17.1%) of the caregivers resided in separate domiciles.

The sample findings in this study show some consistency with other studies. Rusniak and Murphy (1995) reported that 83% of the caregivers in their study were women; Archbold, Stewart, Greenlick, and Harvath (1990) reported that 62% of the caregivers in their study were women; and Caserta, Lund, and Wright (1996) reported that 82% of the caregivers in their study were women. Over 74% of this study's sample of caregivers were 60 years old or older, Rusniak and Murphy (1995) had a sample (n=30) that was comprised of caregivers whose age ranged from 65 years to 84 years old.

Caregiver Symptom Recognition

Caregivers reported a mean of six symptoms experienced by their patients. Fatigue, pain, cough, dyspnea, nausea, and poor appetite were the top six symptoms that caregivers recognized within their patients and reported during the telephone interview prior to death. The next six symptoms (in descending order) that caregivers recognized within their patients and reported during the telephone interview prior to death were trouble sleeping, dry mouth, frequent urination, weight loss, diarrhea, and constipation.

These findings show some consistency with those of Kurtz, Kurtz, Given, and Given (1996), whose caregiver sample identified fatigue, insomnia, loss of appetite, pain, and nausea as the top five symptoms experienced by their patients, and Pickett, Cooley, Patterson, and McCorkle

(1996), whose sample of cancer patients experienced incontinence, cough, pain, nausea, changes in breathing, changes in appearance, fatigue, changes in appetite, inability to sleep, and bowel changes.

The findings related to caregiver reports of pain (n=21, 58%) come close to the findings of Ferrell et al. (1993) who found that two-thirds of all patients with advanced cancer experience significant pain. Kurtz, Kurtz, Given, and Given (1996) that caregivers and patients in their study had a 71% concordance rate for symptom reporting, so it is plausible that caregivers in this subsample may be under-reporting pain in their patients.

Terminally ill, elderly cancer patients are experiencing many untoward effects brought on by the illness and the treatment modalities, and their caregivers are recognizing and reporting the manifestation of these symptoms. The caregiver symptom reports from this secondary analysis are consistent with patient self-reports from other studies. Many of the symptoms that caregivers reported are those that are easily recognized, such as poor appetite, cough, dyspnea, pain, frequent urination, and bowel changes. For a caregiver who does not reside with his/her patient, knowing that the patient experienced difficulty sleeping would require an inquiry by the caregiver. There was no significant difference between caregiver symptom reports when looking at living status, so it is possible that careigvers who do not live with their patients inquire about symptom experiences.

Caregiver Involvement in Symptom Management

The caregivers (n=36) in this study reported their level of symptom assistance at a mean of 2.28 (SD=2.34) symptoms. Symptom assistance was provided for nausea, pain, fatigue, dyspnea, diarrhea, coordination problems, vomiting, poor appetite, weight loss, fever, cough, dry mouth, constipation, frequent urination, arm swelling, and leg swelling. Of interest, caregivers were more frequently involved in managing vomiting, poor appetite, constipation, pain, nausea, and fever at the period between 12 and 24 weeks following entrance into the study. These findings show some consistency with other published research. Ferrell et al. (1993) reported that caregivers for terminally ill cancer patients were involved in managing pain, while Given and Given (1994) discussed the management strategies utilized by the caregivers in their study to alleviate the pain in their patients.

Stetz (1987) reported that 69% of the caregivers under study reported they were involved managing the imposed changes within their patients, such as physical and emotional state alterations. Given and Given (1994) found that caregivers were managing nausea, loss of appetite, and fatigue for their patients, although no percentages/levels of involvement were reported.

Although caregivers in this secondary analysis were involved to some degree in symptom management, the level of unmet needs that was discovered demonstrates that many elderly terminally ill cancer patients may be experiencing great amounts of symptom distress without much involvement in assisting with alleviation from their caregivers. Caregivers may not recognize their role in symptom assistance, or may recognize that a need for symptom management assistance exists, but have a lack of knowledge regarding appropriate symptom management strategies.

Caregiver Perceived Preparedness to Care

The caregivers in this study (n=24) overwhelmingly (67.7%) reported that they felt pretty well or very well prepared to provide symptom management assistance to their patients. Approximately one-third (n=11, 32.3%) of the caregivers reported that they felt not at all or not too well to provide symptom management assistance to their patients. This result was interesting in light of the amount of unmet need with respect to symptom management assistance that was noted in the elderly, terminally ill cancer patients. Global preparedness to care in this study had a mean level of 3.07 (SD=0.49). The concept, preparedness to care, has had little empirical investigation that has been published. Rusniak and Murphy (1995) reported that the caregivers in their sample (n=30) reported a moderate level of perceived preparedness to care, which is consistent with the findings from this study.

In looking at the symptom recognition and symptom involvement results concurrently with the caregivers' perceived level of preparedness, it is apparent that one-third of the caregivers in this sub-sample report that they are not too well or not at all prepared to provide care. These caregivers need assistance in, and time devoted to, gaining the requisite skills to ensure that their patients are receiving the right types and amounts of caregiver symptom management assistance.

Of interest is the other two-thirds of this sub-sample who perceive themselves to be pretty well or very well prepared to care, despite the levels of unmet need that were discovered. In examining the item that was specific to symptom management, the questions mentioned nausea and vomiting as the symptoms. Every patient whose caregiver reported vomiting at the last interview prior to death was assisted by his/her caregiver; 56% (*n*=9) of the patients whose caregivers reported nausea at the last interview prior to death were assisted by their caregivers. Perhaps this group of caregivers is unaware of the knowledge and skills that they do not possess, or define preparedness from a commitment or moral/ethical perspective, resulting in elevated levels of perceived preparedness to care. It is also possible that the preparedness tool that was utilized in the original study did not tap into the symptom management dimension with the level of specificity that was needed. Another point is that the response categories were not sensitive enough. Rather than providing a four-point Likert scale, as is the case with the response categories, perhaps providing respondents with a 10-point scale that ranges from not at all prepared to care, to fully prepared to care would aid in gaining a more accurate picture of the level of preparedness that caregivers perceive they have.

Female caregivers demonstrated slightly higher variability in their perceived preparedness scores (M=2.9, SD=0.7) than males (M=2.7, SD=0.5), and caregivers who resided with their patients demonstrated higher variability (M= 2.9, SD=0.6) than caregivers who lived apart from their patients (M= 2.3, SD=0.3). When applying Chebyshev's Theorem to the results from this secondary analysis, 88.89% of all female caregivers have perceived preparedness levels that fall between 0.8 and 5.0 (the lowest rating possible is 1 and the highest rating possible is 4); 88.89% of all male caregivers have perceived preparedness levels that fall between 1.2 and 4.2; 88.89% of all caregivers residing with their patients have perceive preparedness levels that fall between 1.1 and 4.7; and 88.89% of all caregivers residing apart from their patients have perceived preparedness levels between 1.4 and 3.2. It is clear from this application of Chebyshev's Theorem that caregivers who live apart from their patients report less variability in their levels of perceived preparedness than the other examined sub-sets within this secondary analysis.

Caregiver Gender

Female caregivers dominated this subsample (n= 35, 85.4%), which is consistent with the findings of Rusniak and Murphy (1995), whose caregiver sample was 83% female; Archbold, Stewart, Greenlick, and Harvath (1990), whose caregiver sample was 62% female; and Allen (1994), whose caregiver sample was 53% female. This study demonstrated that female spousal and male spousal caregivers provided about the same amount of assistance with symptoms, whereas female non-spousal caregivers provided slightly more assistance, and the one male non-spousal caregiver in this study was not involved in managing symptoms.

Caregiver Living Arrangements

As was found in the literature, caregivers tended to live with their patients (n=34, 82.9%). Although the literature reviewed dealt specifically with the issue of co-residence and use of formal services, this study did not query for formal service use. Tennstedt et al. (1990) and Tennstedt et al. (1993) found that co-residing caregivers provided more of the informal care. This study found just the opposite to be true: Caregivers who did not reside with the patients were more involved in symptom management than caregivers who did reside with their patients.

Discussion of the Results with the Conceptual Framework

The results of this study, although not statistically significant, do provide a beginning support for the conceptual model, an adaptation of the Social Cognitive

Theory (Bandura, 1986). Caregiver symptom recognition and caregiver involvement in symptom management render the caregiver with the perception that he/she is prepared to care. Because 68% (n=24) had a mean preparedness score of 3.2 (for the item prepared to assist in the management of symptoms), it is possible that for this sub-sample, any amount of symptom management assistance that the caregiver provided brought about positive feelings regarding his/her perceived preparedness to care.

However, based on the findings from this study, the following alterations to the conceptual model are proposed. First, the relationships among the three original concepts, environmental factors, behavioral factors, and personal/cognitive factors will remain linear, but rather than having a uni-directional flow, with environmental factors being the driving force, environmental factors will now be at the center of the model, exerting direct effects upon both behavioral factors and personal/cognitive factors. Second, as with the original model, the behavioral factors will exert direct effects upon the personal/cognitive factors. Finally, recognition of the patient's abilities/limitations must be addressed in order to fully describe the caregiving experience. Because patients are able to participate in greater and lesser amounts of their care at various points in their cancer and treatment trajectories, the design of this study did not provide for those patients who were able to be the sole participants in their symptom management. Thus, patient limitations are being added to the conceptual model, exerting direct effects upon the behavioral factors to account for this important factor (see Figure 3).

Results From the Research Questions

For research question number one, caregiver symptom recognition, caregiver symptom involvement, and the proportion of symptoms that were recognized by the caregiver that the caregiver was involved in managing did not predict levels of perceived preparedness to care for this sub-sample of caregivers. Further, research question number two, the caregiver's gender and living arrangements did not impact the caregivers' perceived preparedness to care in this sub-sample. It is likely that the sample size was not adequate to answer these research questions.

Sixty-eight percent of the caregivers from this sub-sample self report moderately high levels of global perceived preparedness to care, regardless of their care situations and levels of involvement in managing symptoms. It may be possible that caregivers do not know what to do to assist in symptom management, or even that anything can be done on behalf of their patients to alleviate the untoward effects of terminal cancer and/or its treatment modalities.

Implications for Advanced Practice Nursing in Primary Care

The American Cancer Society (1997) estimated that there would be 1,382,400 new cancer diagnoses, with approximately 560,000 deaths due to some form of cancer in 1997. Lung,

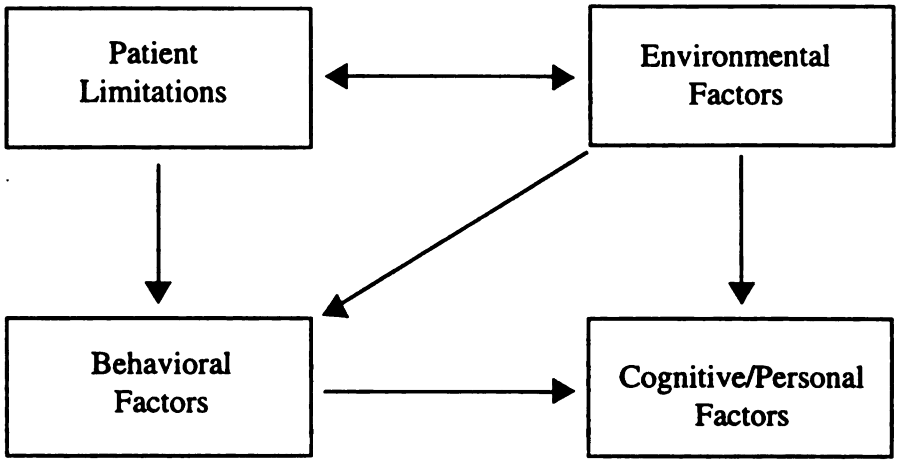

Figure 3. Modification of Study Conceptual Model.

colorectal, breast, and prostate cancers was estimated to account for 825,400 of these new cancer diagnoses and 301,290 of these cancer deaths (American Cancer Society, 1997). Given that these four cancer types were estimated to account for 60% of all newly diagnosed cancers and 54% of all cancer deaths in 1997, the Advanced Practice Nurse (APN) in primary care is in a unique position to foster perceived preparedness in the caregivers for these patients. In order to be successful in this endeavor, the APN must work in partnership with the patient-caregiver dyad. This partnership can be negotiated, established, and nourished through the utilization of the various APN role characteristics, as well as advanced practice nursing interventions.

As an assessor, the APN can utilize data gleaned from the patient's medical record and from face-to-face encounters to complete a comprehensive assessment, through the continuous collection of both subjective and objective data, regarding the status of the patient's biophysical and psychosocial health. Over 75% of this sub-sample of patients had a diagnosis of lung cancer. Patients with lung cancer generally have more rapid deteriorations of their physical health, coupled with shorter survival times. Caregivers for lung cancer patients must be prepared for the physical debilitation and the complex symptom constellations that their patients will experience.

APNs must assess communication patterns between the patient and the caregiver. Knowing first how the patient and caregiver communicate with one another, and secondly how the patient communicates his/her needs to the caregiver will cue the APN if there are breakdowns in communication or mixed messages being sent, or if a pattern of non-communication is the norm. The APN can then utilize counseling techniques to enhance communication between the patient and caregiver, this may facilitate patient-caregiver concordance in symptom recognition/reporting. In this study, unmet needs in symptom management assistance were identified in spite of caregivers reporting high levels of perceived preparedness to care. It is important for APNs to query about symptom experience from the patient's and caregiver's perspective, and then to examine the amount of symptom management assistance that was provided. Although this study did not delve into examining communication patterns within the patient-caregiver dyad, nor did the original study from which this sub-sample was extracted, this information is pertinent in establishing a point of reference from which the plan of care can be developed.

Once the assessment of symptom experience versus symptom recognition and symptom management assistance is completed, the APN should query the caregiver for previous helping behaviors directed on behalf of the patient. Knowing what forms of assistance rendered are acceptable to the patient will provide the APN with the information needed to begin brokering with the patient-caregiver dyad any helping behaviors that are both acceptable to the caregiver to deliver and acceptable to the patient to receive.

The patients in this study were all 65 years of age or older, and nearly two-thirds of the caregivers were 60 years of age or older, these caregivers reported a mean of six symptoms for their patients. The APN must recognize that these patient-caregiver dyads have established patterns of living that are mutually satisfying and meet their individual psychosocial needs. The APN must thoroughly assess for and examine these life patterns and engage the patient-caregiver dyad in an open dialogue to negotiate how to alter this life pattern in a manner that meets the ever changing needs of the patient, without neglecting the needs of the caregiver. Both the original study and this study did not query for types of symptom assistance rendered by the caregivers. The original study did, however, query for the amount of time (in minutes) spent within a two-week time frame prior to the interview that the caregiver or other devoted to providing symptom assistance.

To facilitate the caregiving role acquisition, the APN can utilize role modeling to aid the caregiver in gaining skills in assessment, query for comfort/discomfort level in performing these skills, and provide unconditional positive regard and positive feedback to the caregiver during the skills acquisition phase. Although this study did not identify helping behaviors performed by the caregiver on behalf of the patient, it is important to know what techniques the caregiver has utilized that have been either effective or ineffective in alleviating symptom distress for the patient. Perceived preparedness may be impacted by performing symptom management skills that bring some measure of relief for the patient. It is unknown whether the amount of unmet need noted in this patient sub-sample could be attributed to caregivers who have tried and failed to alleviate symptom distress. Repeated failure in endeavors may elicit an attitude of benign neglect with subsequent same symptom experiences.

One-third of the caregivers in this study were not too well or not at all prepared to care. Based on this finding, the APN must assess the caregiver for any knowledge or training needs related to providing terminal cancer care, and develop a plan that is tailored to meet his/her needs. In addition, it may be necessary for the APN to candidly discuss with the caregiver what his/her role is in the management of the patient's symptoms. Then as the educator, the APN can apply learning theories and various learning methods to teach and assist the caregiver in meeting his/her tasks of care educational needs. Part of this education should include the signs that a patient is experiencing deleterious effects from his/her cancer illness and/or treatment modality(ies), and what symptoms can be safely managed at home versus those that require the attention of a health care professional.

Terminal cancer brings about symptom clusters that tend to evoke potentiating effects on one another. Educating the caregiver on ways to break the cycle of symptom clusters, or alleviating one or two of the symptoms within any cluster, can foster a sense of competence and mastery within the caregiver, bringing about higher levels of perceived preparedness. Caregivers in this study reported an average of six symptoms that their patients experienced, thus a lot of teaching would be required to prepare these caregivers to provide minimal assistance to their patients.

One-third of all caregivers within this study were 70 years of age or older. As people age, their sensory organs have a diminished capacity to perceive and properly register stimuli. Printed information should be of a 12 point font or greater, with black print on buff, non-glossy paper. Verbal instructions should be provided face-to-face, at eye level, and in a lower pitched voice to facilitate hearing and comprehending the instructions. The APN should ask the caregiver to repeat back the information that was provided to ensure that the message was accurately received. Telephone follow-up should be done by the APN, to assess for efficacy of prescribed interventions and caregiver comfort level in providing them.

Within this study, nearly one-third (n=11) of the caregivers perceived that they were not too well or not at all prepared to provide symptom management assistance to their terminally ill patients. Although not queried for in this study, it is important to understand why this number of caregivers felt so ill prepared to provide care and to intervene on their patients' behalf to facilitate a caregiving experience that will provide opportunities for positive self-concept and growth. Caregivers want to feel that they are providing comfort and relief of symptoms to their patients in their final days of life. It is important that the APN assess which caregivers need assistance versus those who may not, and target interventions toward fostering perceived preparedness to care.

As a counselor, the APN must, in some cases, provide the stabilization required to maintain a working relationship between the patient and caregiver. The APN must allow both members of the dyad to vent frustrations, concerns, and fear in a supportive, safe, and confidential atmosphere. Then, the APN must bring the dyad together to openly discuss issues of concern and negotiate resolutions that both patient and caregiver find acceptable. It is through this therapeutic rapport and dialogue that caregivers will receive the support required to continue assuming the role and tasks of care. The caregivers may be experiencing anticipatory grieving over the upcoming death of their loved ones, as well as loss of intimacy in the relationship, while being expected to manage a large number of their patients' symptoms. The APN must be sensitive to this grief process, encouraging caregivers to express their feelings through talking, journal writing, art, music, poetry, or physical activity. Referrals to clergy or a mental health professional may also be indicated to facilitate effective grieving for the caregiver.

The APN must assume the role of the consultant, to provide problem-solving assistance, or information regarding symptom recognition, symptom management assistance, or other tasks of care to the caregiver in order to foster a sense of perceived preparedness within the caregiver. The APN works in partnership with the patient-caregiver dyad, to negotiate a plan of care, based on the priority needs and goals identified by the patient-caregiver-APN triad. It is important that the APN recognizes that the ongoing, day-to-day care needs of the patient are being met by the caregiver. The APN as a collaborator should assist the patient-caregiver dyad with problem-solving management and decision-making regarding the patient's care, including assessing for any community resource or health care system needs to aide in providing the patient's care.

In order to ensure that the caregiver is able to provide the requisite care tasks to the patient, an ongoing assessment must be conducted by the APN regarding the caregiver's skills and knowledge, perceived preparation, and perceived confidence in his/her abilities to continue to provide care. Another important aspect of this is to provide the caregiver with anticipatory guidance and what symptoms are most likely to surface at critical points in the cancer and treatment trajectories.

The APN should assess the patient's confidence in the caregiver's abilities to provide care. This final portion of the assessment, the patient's sense of confidence in the caregiver's abilities may, in all likelihood, provide the fulcrum for this delicate balance. Despite the levels of skill, knowledge, perceived preparedness, and confidence to provide care that a caregiver has, the patient's perception of the care situation and confidence in the caregiver's abilities will determine how the caregiver will approach the care tasks, including which care tasks to perform/provide and which care tasks to defer. This study demonstrated that there exists a large amount of unmet need for symptom management. Thus, the APN must encourage a continuous open dialogue between the patient and caregiver that gives the patient permission to request assistance with symptom management. In addition, the APN may need to teach the patient how to ask for assistance with symptom management. The unmet need discovered through this secondary analysis may be due in part to caregivers not hearing the patients' messages requesting help with symptom management, or to patients not feeling comfortable with or knowing how to ask their caregivers for assistance with symptom management. It may be through this instruction that levels of concordance of caregiver versus patient reported symptoms have the potential to go above the 71% found by Kurtz, Kurtz, Given, and Given (1996).

The APN must continuously evaluate the quantity and quality of care that is provided by the caregiver, utilizing predetermined guidelines and standards, as well as the effectiveness of the care that is rendered by both the caregiver and the APN. This study identified chasms in symptom management assistance delivery (unmet need for the patients) that could have been rectified through an ongoing assessment and evaluation of the home care that was being provided by the caregivers. The APN must reinforce to the caregiver that he/she is a bona fide member of the health care team, and as such, is responsible for providing the care tasks as outline in the negotiated and established plan of care. The caregiver, as a member of the health care team, is accountable to the other team members for providing these care tasks, as well as for monitoring the patient for the effectiveness of the care rendered, and then altering his/her approach to care to facilitate symptom alleviation for the patient.

By assuming these various roles, the APN is acting as a change agent. The systematic and deliberative approach toward working with the patient-caregiver dyad will bring about positive changes within the caregiver's perceived preparedness to care, as well as the caregiver's abilities and approaches to providing care to the elderly, terminally ill cancer patient. Although not every patient-caregiver dyad seen in the primary care setting will involve caregivers who feel not at all or not too well to provide care, the potential to positively impact caregivers who feel pretty well or very well prepared can be realized.

The APN in primary care is equipped with the skills and scientific knowledge to foster perceived preparedness to care in caregivers for elderly, terminally ill cancer patients. Nursing is both art and science, utilizing a holistic approach to the care of humans that encompasses biological, psychosocial, and spiritual domains. This multifaceted approach to human care ensures that each individual's care needs are being met in a way that focuses on and enhances each individual's strengths and assets, while minimizing their weaknesses and liabilities. Perceived preparedness can be approached from any one of the human potential domains. Caregivers can perceive that they are physically prepared; psychologically prepared; socially prepared, through a social support network; and/or spiritually prepared to provide terminal cancer care to an elder. Although this study did not examine these dimensions of preparedness, it is imperative that APNs recognize and address these domains in order to enhance the caregiving experience for the patient-caregiver dyad.

Recommendations for Further Research

As discussed previously in the literature review, a few selected researchers have studied the concept caregiver perceived preparedness, so this study provides an additional view and discussion on the concept. In order to add to the science and body of knowledge on caregiving, and perceived preparedness to care, further inquiry and research is suggested as follows:

1. Further research is needed to examine how a caregiver's perceived control and perceived role tasks impact involvement in patient care and the caregiver's perceived preparedness to care.

It is quite possible that if caregivers do not recognize symptom management as being in the domain of the caregiving role, then unmet need may continue to proliferate within the elderly, terminally ill cancer patient population, as was discovered in this secondary analysis. Likewise, if caregivers do not perceive that they can impact their patients' symptom experiences, as one-third of the sub-sample from this secondary analysis felt, then these caregivers may not attempt to alleviate the deleterious effects of the terminal cancer illness and the treatment modality(ies) being utilized.

2. The development of a cancer care specific preparedness or mastery tool should be completed.

Although it is not yet known if levels of symptom management involvement predict perceived preparedness in caregivers from the original study, the results from this secondary analysis can serve as a pilot study and indicate that the preparedness tool used was neither specific nor sensitive enough to tap into the symptom management dimension of cancer caregiving. It would behoove researchers to query caregivers about the top 15 symptoms that cancer patients experience, to determine how prepared caregivers feel they are to assist in managing nausea versus pain or fatigue. In addition to the individual symptom questions, the response category needs to be a 10-point scale that ranges from not at all prepared to care, to fully prepared to care. This information could be used by health care providers to tailor educational sessions for caregivers who identify preparedness deficits.

3. Further research is needed that examines the relationship between caregiver perceived preparedness to care and depression within the caregiver.

As the trend toward home-based health care continues to expand, more and more family members will be thrust into the role of caregiver. This transition often-time occurs with little to no formal training or education of the caregiver, as well as little fore warning about the impending role acquisition. Caregivers are being asked to assume complex medical and nursing care tasks, symptom management, ADL management, and IADL management, in addition to their current family, employment, and social obligations. This caregiver role is a 24 hours a day, 7 days a week responsibility. It is important for the health care system to know how perceived preparedness to care and depression are related, if at all. Depressed caregivers may be unable to provide the requisite care to the patient and may in fact, cause more harm due to errors in medication administration or errors of omission.

4. Further research needs to be conducted to examine the antecedents to caregiver involvement and reasons why others do not become involved in patient care.

Because health care is being provided in the home setting, it will be imperative that the formal system of care be aware of demographic or psychosocial characteristics that may impact the acquisition of the caregiver role. Likewise, if the reasons for non-involvement in patient care

are brought to the forefront, interventions can be initiated to possibly remedy this type of situation. When there is a greater number of secondary caregivers involved in the patient's care, the likelihood that the primary caregiver is able to be engaged in social and leisure activities increases, thus increasing likelihood that the primary caregiver will be able to continue with his/her caregiving role. Concurrent querying should be conducted to examine what interferes with the caregivers' recognition of symptom management needs.

5. Further research should be conducted that examines patterns of caregiver helping behaviors and how patients and caregivers broker: 1) the caregiving role, 2) accepted helping behaviors, and 3) which symptoms caregivers are willing to assist in managing and which symptoms caregivers are not willing to assist in managing.

This information can be utilized in caregiver educational groups. Knowing the average care needs for an elderly lung or breast cancer patient may help to alleviate fear of role overload for new caregivers. Knowing how other patient-caregiver dyads have negotiated what helping behaviors will be provided by the caregiver and what helping behaviors are acceptable to the patient <u>and</u> caregiver may facilitate a similar open dialogue between other patient-caregiver dyads, fostering an esprit de corps, or at the very least, beginning the journey of the care trajectory from the same reference point.

6. Further research needs to be conducted, utilizing a qualitative research design, that examines caregiver workload, caregiver perceived preparedness to provide the requisite care tasks over time, caregiver perceived health care system needs, and caregiver perceived education/training needs.

This information can be utilized to broaden the knowledge base regarding the caregiving experience. Although a vast amount of information exists on caregiving in general, much it is collected using instruments that have response categories with four to five options for selection. Not all caregiving experiencing can be cataloged within the same defined confines. Open ended questions that do not have predetermined response categories, afford the caregiver with the latitude to discuss his/her unique care situation, perceived abilities/preparedness to care, and needs in order to continue the caregiving role. Exposing the caregiver to this means of data collection may engender feelings of contribution or importance within the caregiver, with respect to the research process, or feelings that there is genuine interest in learning about the caregiver's unique situation and perspective of the caregiving role. If health care providers know how prepared, or ill prepared, a caregiver feels to provide care, then interventions to enhance preparedness can be initiated. This open dialogue from the caregivers will expand and enrich the current level of knowledge, provide information to the health care system so that it can intervene on the caregiver's behalf, and perhaps create new avenues for scientific inquiry.

7. A replication of this study needs to be conducted with a larger sample that tracks preparedness across time in order to determine if a larger sample will produce similar, or different results.

It is important that all research endeavors are initiated with the goal of replication, whether it be performed by the same researcher or someone else. The validity of a study's findings are enhanced when results can be replicated in subsequent inquiries. Likewise, if alternative results are obtained from a replication, then it is important to investigate for extraneous variables that may be impacting the outcome measures, and if found, attempt to control for these extraneous variables in the data analysis. The pursuit of empirically valid findings must be the goal of all researchers.

Summary

This study examined caregiver symptom recognition in, and levels of caregiver symptom management assistance provided to elderly, terminally ill cancer patients at the interview wave prior to death, to determine if these impacted caregiver perceived preparedness to care. This study further sought to determine if caregiver gender or living arrangements further impacted caregiver perceived preparedness to care. The findings from this secondary analysis suggest that none of the independent variables impacted caregiver perceived preparedness to care at a statistically significant level.

The majority of caregivers perceive themselves to be pretty well prepared to care in this sub-sample. Caregivers are recognizing an average of six symptoms in their patients, yet providing assistance for an average of only two, leaving four deleterious effects from the terminal cancer illness, or treatment modality(ies) unaided in their elderly, terminally ill, cancer patients. Despite the findings that were not statistically significant, one-third of the sub-sample of caregivers in this study reported that they were not too well or not at all prepared to provide care. This finding suggests that perhaps there are other extraneous variables not examined in this secondary analysis that drive perceived preparedness levels. Co-morbidity within the patient sample was not examined, nor was caregiver physical or mental health status examined.

An interesting finding from this secondary analysis was that although caregivers were recognizing about the same number of symptoms within their patients, the caregivers who did not live with their patients provided more symptom management assistance than did those caregivers who resided in the same domicile as their patient. Although previous discussion surrounded issues regarding goal directed care related to competing role demands experienced by that subset of caregivers, another plausible explanation is that caregivers who live with elderly, terminally ill cancer patients may become desensitized to their patients' symptom experiences. If this is the case, then it seems to be a logical finding that those caregivers who do not reside with their patients not only recognize the deleterious effects, but also take action to alleviate them.

The continued movement of health care provision to the home setting is an effort on the part of insurance companies to attempt to corral the out of control costs of inpatient health care. As Medicare continues to try to control costs and maintain a solvent system of health care by cutting allowable services, such as home health care nurses, the responsibility of providing terminal cancer care to elders will continue to shift to family members of the patient. The challenge that faces the formal system of care lies in making this transition of care provision a seemingly effortless event.

Advanced practice nurses are in the unique position to demonstrate their mettle, and worth, vis a vis other health care providers, in ensuring that this transition of care is completed without compromising the well being of either member of patient-caregiver dyad. Nursing is the art and science of providing holistic care to systems, whether these systems be singular, the family, a community, or society as a whole. Nurses in advanced practice have the advanced training, skills, and knowledge to provide comprehensive care based on ongoing assessment, diagnostics, care planning, advanced interventions, and evaluation for the quality, completeness, and appropriateness of the care provided. A key component in this scheme is the caregiver, who provides the APN with his/her subjective appraisal of the patient's status between visits. Assuring that caregivers are prepared biophysically, psychologically, socially, and spiritually to provide the requisite care tasks, is paramount to the delivery of quality care to the elderly, terminally ill, cancer patient in the home setting. APNs are called upon to utilize this opportunity to improve the home cancer care experience for all patient-caregiver dyads through their quintessential caring skills.

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APPENDIX A

NINR/NCI WAVE III CAREGIVER W/ PATIENT TELEPHONE

ID __ __ __ __/INT __
DATE __ __/__ __/__ __

CAREGIVER SYMPTOM ASSISTANCE

We want to ask you about symptoms related to cancer or treatment that your _______ may have experienced in the past two weeks. First, we would like to know if your _______ complained of the symptom, if you or anyone else did anything to try to relieve the symptom, and, if so, how many minutes you or others devoted to the task of relieving the symptom (estimated). Remember, the assistance provided should include both the time spent with the patient such as comforting, observing for effect, and direct care as well as other time spent in activities such as preparing food or medications, obtaining special supplies or equipment, or other activities where the goal was to help relieve your _______'s symptom. Please include time comforting or sitting with your _______, giving backrubs, talking with doctors or others, getting medicines, or any effort directed toward symptom relief.

In the past two weeks has your _______ had any of the following symptoms?

A. Symptom	B. Complain of in past two weeks?		C. Did you/anyone assist patient?		D. Total number of minutes in past two weeks?
	YES (1)	NO (2)	YES (1)	NO (2)	(write in total minutes)
	(circle one)		(circle one)		
	1	2	1	2	____ minutes
1. Nausea.	1	2	1	2	____ minutes
2. Pain.	1	2	1	2	____ minutes
3. Trouble sleeping.	1	2	1	2	____ minutes
4. Fatigue.	1	2	1	2	____ minutes
5. Difficulty breathing/ shortness of breath.	1	2	1	2	____ minutes
6. Diarrhea.	1	2	1	2	____ minutes
7. Coordination problems.	1	2	1	2	____ minutes
8. Vomiting.	1	2	1	2	____ minutes
9. Poor appetite.	1	2	1	2	____ minutes

NINR/NCI WAVE III CAREGIVER W/ PATIENT TELEPHONE

ID ____/INT _
DATE __/__/__

A. Symptom	B. Complain of in past two weeks? YES (1)	B. Complain of in past two weeks? NO (2)	C. Did you/anyone assist patient? YES (1)	C. Did you/anyone assist patient? NO (2)	D. Total number of minutes in past two weeks? (write in total minutes)
	(circle one)		(circle one)		
	1	2	1	2	____ minutes
10. Weight loss.	1	2	1	2	____ minutes
11. Fever.	1	2	1	2	____ minutes
12. Cough.	1	2	1	2	____ minutes
13. Dry mouth.	1	2	1	2	____ minutes
14. Constipation.	1	2	1	2	____ minutes
15. Frequent urination.	1	2	1	2	____ minutes

(GO TO NEXT SECTION)

APPENDIX B

The following questions ask you to consider how well prepared you feel for a number of caregiving activities for your relative/friend. For each item please indicate the following:

Overall, how well prepared do you feel you are ...
Would you say ... (circle one response for each)

1 = NOT AT ALL PREPARED
2 = NOT TOO WELL PREPARED
3 = PRETTY WELL PREPARED
4 = VERY WELL PREPARED

How well prepared do you feel you are ... (circle one response for each)

		NOT AT ALL PREPARED	NOT TOO WELL PREPARED	PRETTY WELL PREPARED	VERY WELL PREPARED
1.	to care for _____'s physical needs (e.g. dressing, toileting, bathing, etc.)?	1	2	3	4
2.	to take care of _____'s emotional needs?	1	2	3	4
3.	to find out about and set up formal services for _____'s care?	1	2	3	4
4.	to care for _____'s medical/nursing treatments (e.g., giving medicines, changing dressings, skin care, exercises, etc.)?	1	2	3	4
5.	to manage finances, bills, and insurance forms related to _____'s care needs?	1	2	3	4
6.	to plan for activities such as rest, meals, recreation, or things for _____ to do?	1	2	3	4
7.	to manage _____'s behavior problems, such as moodiness, irritability, and confusion?	1	2	3	4
8.	to manage equipment and techniques necessary to care for _____?	1	2	3	4
9.	to help in management of symptoms such as nausea or vomiting?	1	2	3	4
10.	to discuss with doctors the problems _____ is having?	1	2	3	4
11.	to help _____ get to cancer treatments?	1	2	3	4
12.	to find the information that you need about cancer?	1	2	3	4
13.	Overall, how well prepared do you think you are for the role of caregiving?	1	2	3	4

APPENDIX C

MSU FAMILY HOME CARE CANCER STUDY

CAREGIVER CONSENT FOR RESEARCH

Introduction

You are being asked to participate in a research project to study the costs associated with cancer and the effects of cancer on the lives of patients and their families or caregivers. The purpose of this research study is to determine how age, preexisting health conditions, the site and extent of the cancer, and the type of treatment affects the patient's mental status and ability to perform usual daily activities. In addition, information concerning the involvement of and effect on patient's families or caregivers will be collected.

This study is being conducted by Drs. Barbara and Charles Given who are professors in the College of Nursing and the Department of Family Practice at Michigan State University. This research study is being sponsored by Michigan State University and also involves other hospitals or medical center. This study will involve 1,235 patients 65 years of age and older who have breast, colon, lung or prostate cancer.

Description of Procedures

Should you decide to participate you will be contacted by telephone four times over the next 12 months; at approximately 4, 12, 24 and 52 weeks following your friend or family member's diagnosis. The trained interviewer who will call you will ask a number of questions about your health, how you are feeling, the types of activities you help your friend or family member perform, and the amount of time and money you spend in caring for this person. It will take about 45-60 minutes to complete each interview. In addition, a written questionnaire will be sent to you with a stamped return envelope. This questionnaire will ask questions regarding the assistance you provide to your friend or relative and will take about 15 minutes to complete.

Risks and Discomforts

It is not expected that you or your friend or family member will be placed at any physical, financial or legal risk as a result of participation in this study. Regardless of whether or not you choose to participate in this study, you and your friend or family member will continue to receive medical care under the direction of his/her personal physician(s). All information collected for this study including that obtained from your friend or family member will be kept strictly confidential.

It is recognized that the diagnosis and treatment of cancer is stressful. In over 400 cancer patients, the investigators have found no patient to date who experienced additional stress as a result of responding to similar interview questions or written questionnaires. All interviewers for this study will be trained by the investigators, and will be able to assist you if you should find any aspect of this study upsetting. In addition, you are free to withdraw from this study at any time for any reason without penalty or change in the quality of medical care which you receive. If you have any questions or wish to withdraw from the study you may call either the project coordinator or Charles W. Given, the Co-Principal Investigator, at the research office: (517) 353-3843 or toll free, 1-800-654-8219.

Benefits

It is not expected that you or your friend or family member will experience any direct benefit from participation in this study. Information from this study may provide useful information concerning the personal and financial impact of the diagnosis and treatment of four common cancers among the elderly. Neither you nor your friend or family member will be paid or receive any other form of compensation for participating in this study.

Alternatives

If you decide not to participate in this study your friend or family member will continue to receive all medical care and other standard forms of support. Neither you nor your friend or family member will be contacted for telephone interviews or asked to complete questionnaires.

Rights and Responsibilities

To take part in this study, you must choose to do so and sign this form on the line below. Only volunteers will be used in this study. If you choose to be in the study now, you may withdraw later on by calling Dr. Charles W. Given at (517) 353-3843 or toll free, 1-800-654-8219. If you choose not to take part in this study, or if you withdraw after you have started, you will not be penalized in any way.

A record of your progress while on the study will be kept in a confidential file at College of Nursing at Michigan State University. Only a few people who work on the study will have access to records that could directly or indirectly identify you. Information about your participation in this study will be combined with that of all other patients who participate in the study and may be shared with others in the research field, but no names will be used. There will be no names or other patient identification used in any study reports published later on.

In the unlikely event of any injury from the research, no reimbursement, compensation or free medical treatment is offered by Michigan State University.

Should you have any questions about your rights as a subject or should you sustain any injury related to the research, you may contact Dr. David Wright, Chair, University Committee on Research Involving Human Subjects, at (517) 355-2180.

I have had an opportunity to ask questions about the study and was given sufficient time to consider my participation. I have received a copy of this form and agree to participate.

Caregiver's Signature______________________Date__________

Please print:

name ______________________________

address______________________________

____

phone (____)______________________________

Name of patient _________________________

Investigator's Signature_____________________Date__________

Witness' Signature_______________________Date__________

UCRIHS APPROVAL FOR
THIS project EXPIRES:

MAY - 8 1998

SUBMIT RENEWAL APPLICATION
ONE MONTH PRIOR TO
ABOVE DATE TO CONTINUE

wp: \CG-MSU (3/97)

APPENDIX D

MICHIGAN STATE
UNIVERSITY

May 12, 1997

TO: Barbara A. Given
A230 Life Sciences

RE: **IRB#:** 92-280
TITLE: FAMILY HOME CARE FOR CANCER--A COMMUNITY-BASED MODEL
REVISION REQUESTED: N/A
CATEGORY: 1-C, 2-H
APPROVAL DATE: 05/08/97

The University Committee on Research Involving Human Subjects' (UCRIHS) review of this project is complete. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and methods to obtain informed consent are appropriate. Therefore, the UCRIHS approved this project and any revisions listed above.

RENEWAL: UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Investigators planning to continue a project beyond one year must use the green renewal form (enclosed with the original approval letter or when a project is renewed) to seek updated certification. There is a maximum of four such expedited renewals possible. Investigators wishing to continue a project beyond that time need to submit it again for complete review.

REVISIONS: UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. If this is done at the time of renewal, please use the green renewal form. To revise an approved protocol at any other time during the year, send your written request to the UCRIHS Chair, requesting revised approval and referencing the project's IRB # and title. Include in your request a description of the change and any revised instruments, consent forms or advertisements that are applicable.

PROBLEMS/ CHANGES: Should either of the following arise during the course of the work, investigators must notify UCRIHS promptly: (1) problems (unexpected side effects, complaints, etc.) involving human subjects or (2) changes in the research environment or new information indicating greater risk to the human subjects than existed when the protocol was previously reviewed and approved.

If we can be of any future help, please do not hesitate to contact us at (517)355-2180 or FAX (517)432-1171.

Sincerely,

D. E. Wright

David E. Wright, Ph.D.
UCRIHS Chair

DEW:bed

cc: Charles Given ✓

OFFICE OF
RESEARCH
AND
GRADUATE
STUDIES

University Committee on
Research Involving
Human Subjects
(UCRIHS)

Michigan State University
246 Administration Building
East Lansing, Michigan
48824-1046

517/355-2180
FAX: 517/432-1171

APPENDIX E

MICHIGAN STATE
UNIVERSITY

October 16, 1997

TO: Barbara A. Given
A230 Life Sciences

RE: IRB#: 97-678
TITLE: THE IMPACT OF CAREGIVER SYMPTOM INVOLVEMENT ON LEVELS OF PERCEIVED PREPAREDNESS AND DEPRESSION IN CAREGIVERS FOR ELDERLY, TERMINALLY ILL CANCER PATIENTS
REVISION REQUESTED: N/A
CATEGORY: 1-E
APPROVAL DATE: 10/14/97

The University Committee on Research Involving Human Subjects' (UCRIHS) review of this project is complete. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and methods to obtain informed consent are appropriate. Therefore, the UCRIHS approved this project and any revisions listed above.

RENEWAL: UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Investigators planning to continue a project beyond one year must use the green renewal form (enclosed with the original approval letter or when a project is renewed) to seek updated certification. There is a maximum of four such expedited renewals possible. Investigators wishing to continue a project beyond that time need to submit it again for complete review.

REVISIONS: UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. If this is done at the time of renewal, please use the green renewal form. To revise an approved protocol at any other time during the year, send your written request to the UCRIHS Chair, requesting revised approval and referencing the project's IRB # and title. Include in your request a description of the change and any revised instruments, consent forms or advertisements that are applicable.

PROBLEMS/ CHANGES: Should either of the following arise during the course of the work, investigators must notify UCRIHS promptly: (1) problems (unexpected side effects, complaints, etc.) involving human subjects or (2) changes in the research environment or new information indicating greater risk to the human subjects than existed when the protocol was previously reviewed and approved.

If we can be of any future help, please do not hesitate to contact us at (517)355-2180 or FAX (517)432-1171.

Sincerely,

David E. Wright, Ph.D.
UCRIHS Chair

DEW:bed

cc: Sharon L. Kozachik

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