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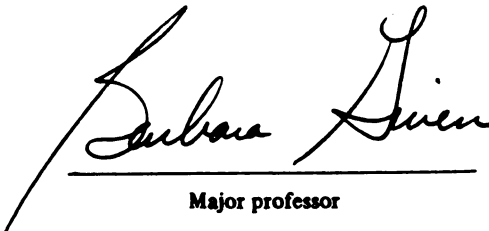
THE CAREGIVER'S PERCEPTION OF THE TASKS OF CARE
NEEDED BY PATIENTS WITH LATE STAGE LUNG
CANCER AND COLORECTAL CANCER

presented by

Mary Beth Adyniec

has been accepted towards fulfillment
of the requirements for

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**THE CAREGIVER'S PERCEPTION OF THE TASKS OF CARE
NEEDED BY PATIENTS WITH LATE STAGE LUNG
CANCER AND COLORECTAL CANCER**

By

Mary Beth Adyniec

A THESIS

**Submitted to
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ABSTRACT

THE CAREGIVER'S PERCEPTION OF THE TASKS OF CARE NEEDED BY PATIENTS WITH LATE STAGE LUNG CANCER AND COLORECTAL CANCER

By

Mary Beth Adyniec

The treatment of patients with cancer has shifted from the hospital to outpatient services and home where caregivers are taking increased responsibility for the care. This secondary analysis identifies and describes specific tasks of care provided by caregivers for patients with late stage lung and colorectal cancer in the initial phase of treatment. Specific tasks of care are divided into three broad categories: Activities of Daily Living, Activities of Symptom Management Assistance, and Activities of Health Care Assistance.

The findings revealed that caregivers of patients with lung and colorectal cancer frequently provide assistance with many of the same tasks of care. Patients with lung cancer had more need for assistance overall, especially Activities of Daily Living. Patients with colorectal cancer required more assistance with Activities of Health Care. Advanced practice nurses can use these findings to develop interventions to assist caregivers caring for patients with lung or colorectal cancer.

This study is dedicated to my husband, Alan, and my children, Emily, Michelle and Anne.

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INTRODUCTION

Approximately 7.4 million Americans alive today have had a diagnosis of cancer (American Cancer Society, 1997). Lung cancer and colorectal cancer are the second and third most prevalent diagnoses respectively (Garfinkel, 1995). An estimated 309,300 men and women will be diagnosed with lung and colorectal cancer in 1997, all of whom will require treatment within the health care system (American Cancer Society, 1997). However, much of this treatment has shifted from the hospital to outpatient services and the home where family caregivers are taking increased responsibility for the care of the patient with cancer (Given & Given, 1994). Caregivers are providing the necessary care for the patient during rehabilitation from surgery, during the treatment regimens, and during the advanced phases of the illness (Stetz, 1987). Caring for patients with cancer in the home can be accomplished with lower costs to the health care system (Siegel, Raveis, Houts, & Mor, 1991), but at what cost to the patients with cancer and their caregivers? A better understanding of the tasks of care needed by patients with cancer and provided by caregivers is important because, if caregivers become overburdened, they may be unable to

continue to provide the care proposed by the health care provider and needed by the patient (Varricchio, 1994).

Background of the Problem

What are the specific tasks of care needed by the patient with cancer that caregivers are providing at home? Most of the studies involving caregivers of cancer patients focus on the emotional aspects of stress, coping, and adjustment related to the demands of care (Tringali, 1985; Oberst, Thomas, Gass, & Ward, 1989; Blank, Clark, Longman, & Atwood, 1989), but few studies have focused on the specific tasks of care needed by patients with cancer. This study identifies the tasks of care within three broad categories of care most frequently provided by caregivers for patients with late stage lung cancer and colorectal cancer. This information may be used by advanced practice nurses and other health professionals to assist caregivers of patients with cancer in the planning and delivery of necessary care.

Tasks of Care

In situations where self-care is inadequate, caregivers must assist the patient by providing necessary tasks of care (Given & Given, 1995). Tasks of care are the physical assistance activities caregivers engage in to meet the needs of patients with cancer. The tasks of care can be provided by one or several different caregivers. The primary caregiver identifies the tasks of care provided for the patient in this study. The type of care provided can

encompass a variety of different tasks of care. These different tasks of care are grouped into three broad categories of care which include Activities of Daily Living Assistance, Activities of Symptom Management Assistance, and Activities of Health Care Assistance.

The Activities of Daily Living/Instrumental Activities of Daily Living Assistance category of care involve assisting with activities of daily living (ADL), such as, bathing, dressing, and toileting. In this category, caregivers may also assist with instrumental activities of daily living (IADL), such as transportation, cooking, and housework.

The Activities of Symptom Management Assistance category tasks of care involve assistance with activities devoted to relieving symptoms the patient is experiencing related to the disease and/or treatment (Given & Given, 1991). Some of these activities are pain, nausea, and poor appetite.

The Activities of Health Care Assistance category tasks of care involve assistance with complex treatment activities that extend from the health care center to home (Mor, Guadagnoli, & Wool, 1988; Tringali, 1985), such as, care of special intravenous access devices, tube feedings, injections, and wound care.

Lung Cancer and Colorectal Cancer

The site of cancer may impact the tasks of care provided by caregivers. Lung cancer has a 5-year survival

rate of only 14% which signifies a rapid deterioration (American Cancer Society, 1997). A surgical resection is the treatment of choice for cancer of the lung with the intent of cure (Humphrey, Ward, & Perri, 1995). However, only about half of the patients diagnosed with lung cancer will be operable at diagnosis due to the extent and location of the cancer. Radiation therapy or chemotherapy may be used alone or in combination after surgery, or if surgery is not possible. The goal of these treatments are to increase survival time, and are also effective in relieving pain and other symptoms. Therefore, the rapid physical decline of the patient with lung cancer, the side effects of the treatments which may or may not include surgery, and the need for frequent visits to health care facilities for evaluation and treatment may result in several different tasks of care needing caregiver assistance.

Colorectal cancer has a much different course than lung cancer. Colorectal cancer has an overall 5-year survival rate of 61% and is marked by a more unpredictable disease course than lung cancer (American Cancer Society, 1997). The primary treatment for colon and rectal cancer is surgery (Steele, 1995). The goal of surgery is to remove the section of bowel containing the tumor, the surrounding tissue, and possibly the lymph nodes draining the area with the intent of cure. In some cases, a temporary colostomy is needed. Less than 15% of patients with colorectal cancer require a permanent colostomy. Radiation therapy may also

be used before surgery to reduce the size of the tumor and to increase the likelihood of surgical removal, and after surgery to destroy remaining malignant cells. Chemotherapy is used to help prevent recurrence and to reduce tumor size and relieve pain. The recuperation period for the patient colorectal cancer related to probable surgery and possibly a colostomy, the side effects of the treatment regimen, and the need for frequent visits to health care facilities may require assistance with tasks of care from family caregivers in several different areas.

Stage of Cancer

The stage of cancer at diagnosis may also impact the tasks of care provided by caregivers. A standardized staging nomenclature, accepted worldwide, for all primary sites has been established as the TNM system (Lenhard, Lawrence, & McKenna, 1995). The size and extent of the involvement of the local neoplasm (T), the presence or absence and extent of regional lymph node metastasis (N), and the presence or absence of distant metastasis (M) determine the stage of the cancer. Stage III and stage IV are considered late stage disease.

About 85% of patients with lung cancer have disease that is not confined to the lung at diagnosis (American Cancer Society, 1997). Therefore, the majority of patients with lung cancer are determined to be late stage at diagnosis and their survival is significantly compromised.

While colorectal cancer survival rates are potentially much better than lung cancer survival rates, some people delay following up on symptoms of colorectal cancer resulting in the spread of the cancer to regionalized organs and lymph nodes. This results in a reduced 5-year survival rate of 63%, compared to a 5-year survival rate of 91% when colorectal cancer is detected in an early localized stage (American Cancer Society, 1997). The 5-year survival rates for persons with distant metastases are less than 7%.

In the late stage of illness for patients with lung cancer or colorectal cancer, the care requirements may initially center around the therapeutic treatment of the patient. This would probably include surgery for most of the patients with colorectal cancer and to a lesser extent the patients with lung cancer. Post-surgical care requires a rehabilitation period with weakness, pain, wound care, and colostomy care for some of the patients with colorectal cancer.

Radiation therapy and chemotherapy alone and in combination may also be part of the initial treatment program for patients with late stage lung or colorectal cancer. Radiation therapy requires transportation to and from the site of administration on a daily basis, usually for 6-8 weeks. The side effects of radiation therapy may include, fatigue, skin irritations, nausea, and vomiting that persist well after treatment is completed.

Chemotherapy may be given at scheduled intervals at a clinic. This involves a treatment being given with a 3-4 week recovery period, followed by another treatment and so on. Usually, several cycles over a 6 month period are given. Frequently, other medications are given concurrently for pain and nausea through an intravenous port requiring monitoring and care. The side effects of chemotherapy often include nausea, vomiting, decreased white blood cell counts resulting in fatigue and increased risk of infection.

Although these regimens are therapeutic in nature, side effects can result in the debilitation of an already compromised patient. The deterioration of the patients condition may or may not result in the discontinuation of these treatments, however, there are frequently intensified physical needs of the patient requiring around-the-clock care, usually provided by family members.

The patients physical functional ability, symptom experience, and health care requirements are affected by the cancer diagnosis and stage of disease. The care that caregivers provide at home for these patients can be extensive and exhaustive. It is important to identify the specific tasks of care within broad categories of care most frequently needed by patients with late stage lung and colorectal cancer and provided by caregivers.

CONCEPTUAL FRAMEWORK

The underlying assumption in this study is that the patient's site of cancer and stage of disease influence the

tasks of care within categories needed by patients with cancer and provided by caregivers. Conceptually, this study was guided by the Continuing Cancer Care Demands and Family Caregiver Burden Model (Given & Given, 1995). This model identifies several factors effecting caregiver responses to providing care for a family member with cancer (See Figure 1). These factors influence how caregivers deal with the difficulty of providing ongoing and continuous care for patients with cancer. The factors in this model include the Background of Family identifying prior family relationships, family networks, family developmental stage, socioeconomic status and living arrangement. The Characteristics of the patient and caregiver identify age, gender, marital status, role obligations, resources and co-morbid conditions of the patient. The Nature of Cancer identifies the effects of the disease and treatment related to the site, type, and stage of cancer which result in patient needs and care requirements. The Informal Care System of family and friends and the Formal Care System of acute care, visiting nurse services (VNS), home care, and hospice identify supports for the patient and caregiver influencing the demands they experience. The demands on the caregiver and patient include patient symptom experience, patient activities of daily living, other patient role dependency, and medical care tasks required by the patient and provided by the caregiver. The caregiver outcome variable focuses on the effect all of these variables have on caregiver burdens

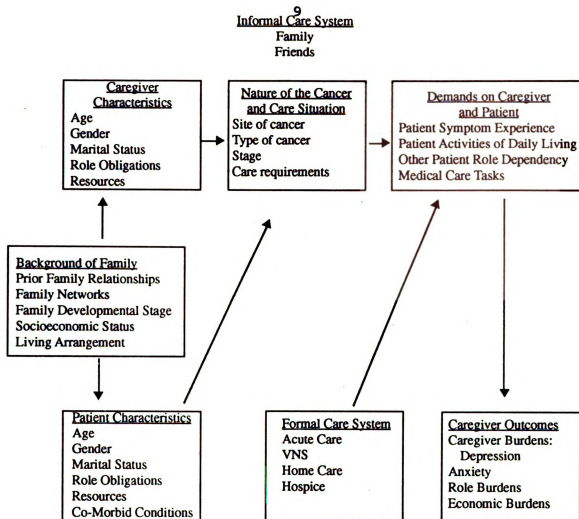


Figure 1. Continuing Cancer Care Demands and Family Caregiver Burden Model (Grant #1-R01-NR01915 Funded by the National Institute of Nursing Research and the National Cancer Institute

including depression, anxiety, role burdens and economic burdens.

This study will only focus on the factors involving the Nature of the Cancer and the Demands on Caregiver and Patient (See Figure 2). The Nature of the Cancer includes the site and stage of cancer at diagnosis. The site and stage of cancer are important in determining the course of the disease. The different sites of cancer being examined in this study are lung and colorectal. However, both groups of patients have late stage disease. Different cancer sites have somewhat predictable patterns of illness. The stage of cancer at diagnosis will also influence the course of the disease. The patient with late stage lung cancer can anticipate one or more treatment modalities, frequently with only minimal results and a progressive decline in health and functional ability. The patient with late stage colorectal cancer can also anticipate several treatment modalities with better rates of survival than the late stage lung cancer patient. The course of late stage colorectal disease may have periods of exacerbation with reduced health and functional ability followed by periods of remission with improved health and functional status.

The Demands on Caregiver and Patient from the original model is referred to as Caregiver Assistance Activities and focuses on the tasks of care within three categories of care provided for patients with cancer by their caregivers (see figure 2). The three categories of care were derived from

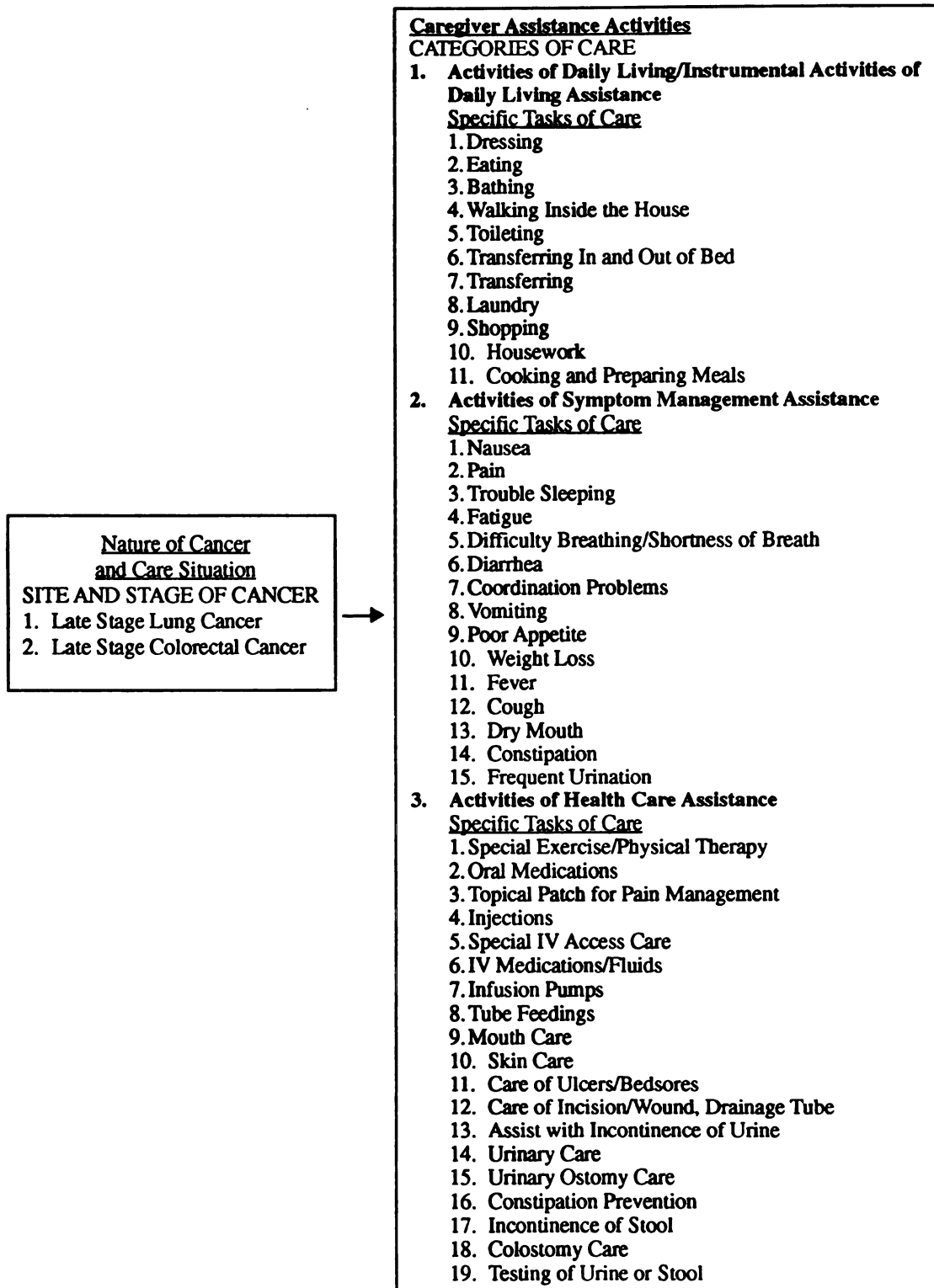


Figure 2. Proposed Model for Caregiver Assistance Activities Provided by Caregivers of Patient with Cancer.

the patient symptom experience, patient activities of daily living, and medical care tasks variables from the original model. The titles of these variables have been modified slightly for this study with the Patient Activities of Daily Living variable referred to as Activities of Daily Living/Instrumental Activities of Daily Living Assistance, the Patient Symptom Experience variable referred to as Activities of Symptom Management Assistance, and the Medical Care Tasks variable referred to as Activities of Health Care Assistance. The specific tasks of care within the categories of care include: 1) the Activities of Daily Living/Instrumental Activities of Daily Living Assistance of dressing, eating, bathing, walking inside house, toileting, transferring in and out of bed, transportation, laundry, shopping, housework, and cooking and preparing meals; 2) the Activities of Symptom Management Assistance of nausea, pain, trouble sleeping, fatigue, difficulty breathing, diarrhea, coordination problems, vomiting, poor appetite, weight loss, fever, cough, dry mouth, constipation, and frequent urination; and 3) the Activities of Health Care Assistance of physical therapy, oral medications, topical patch for pain management, injections, special IV access care, IV medications, infusion pumps, tube feedings, mouth care, skin care, care of ulcers/bedsores, care of incision/wound, drainage tube, dressings, assist with incontinence, urinary catheter care, urinary ostomy care, constipation prevention, incontinence of stool, colostomy care, and testing of urine

and stool. The Caregiver Assistance Activities will be effected by the Nature of the Cancer variables.

STATEMENT OF PURPOSE

The purpose of this study is to identify and describe the caregiver's perceptions of tasks of care, within three broad categories of care, needed by patients with late stage lung and colorectal cancer. This study may also provide information about any differences in tasks of care required and provided by caregivers for patients with late stage lung cancer compared to patients with late stage colorectal cancer. The identification of these tasks of care provided by caregivers and any differences based on diagnosis, may be helpful to health care providers, including advanced practice nurses, in the management of care and development of programs to support patients with cancer and their caregivers.

Specifically, the research questions for this analysis are:

1. Within each of the three categories of care, which are the most frequently occurring specific tasks of care that patients with late stage lung cancer and late stage colorectal cancer require assistance with as reported by caregivers?

2. Are there differences between patients with late stage lung cancer and patients with late stage colorectal cancer in the average number of specific tasks of care for

which assistance is required, as reported by caregivers, in each of the three categories of care?

REVIEW OF LITERATURE

The review of literature involving tasks of care needed by patients with cancer and provided by caregivers over the past 5 years has been limited. Most studies determine needs broadly related to psychological, social, informational, and physical dimensions. Physical care needs are consistently identified by patients and caregivers. However, these needs are not specific and do not provide information regarding types of physical care required. The studies do not differentiate site or stage of cancer related to tasks of care provided by caregivers.

Activities of Daily Living/Instrumental Activities of Daily Living Assistance Tasks of Care

Most of the research regarding the physical care needs of patients provided by caregivers focus on activities of daily living (ADL) and instrumental activities of daily living (IADL). Wingate and Lackey (1989) described the needs of 33 cancer patients and their caregivers using the same category of needs. The sample consisted of three groups of adult subjects which included non-institutionalized cancer patients, primary caregivers of non-institutionalized cancer patients, and nurses with experience working in a home care agency. The 10 cancer patients in the sample had varied diagnoses. The results of the study reported that for both patients and caregivers,

the largest area of need was in the psychological category. For patients, the physical need category was next followed by the need for information. For caregivers in the study, the household management category which encompassed patient care was identified as the second greatest need followed by informational needs.

Hileman and Lackey (1990) identified the needs of 15 patients with cancer at home and their 15 caregivers from 505 need statements. The patient category of needs included informational, household management, psychological, spiritual, legal, financial, and other needs. Patients greatest needs were psychological, physical, and informational. Caregivers greatest needs were psychological, information, and those related to household duties. The household category included anything that relates to managing or running a household and providing patient care.

Hileman, Lackey, and Hassanein (1992) used a slightly modified version of these categories with 492 caregivers of patients with cancer at home. The categories in this study were informational, household, patient care, personal, spiritual and psychological. Patient care was separated out of the household duty category. These caregivers identified psychological, informational and patient care needs most frequently.

Mor, Allen, Siegel, and Houts (1992) identified the daily living needs of 629 patients with advanced disease

initiating a course of outpatient chemotherapy and/or radiation therapy. Slightly more than half of the sample (51%) reported a need for assistance with instrumental tasks of care. A higher proportion of patients (58%) reported needing help with transportation. Only 14% of the patients reported needing assistance with personal tasks of care.

The studies that examine activities of daily living and instrumental activities of daily living consistently identified caregivers providing household needs and patient care needs for the patient (Hileman & Lackey, 1990; Hileman, Lackey, & Hassanein, 1992; Wingate & Lackey, 1989).

However, these activities are identified broadly and may cover a wide range of specific activities that the caregiver may be required to provide. When Mor et al. (1992) identified transportation as a separate category of need this activity was frequently reported as being required by patients with cancer. Therefore, it is important to identify those specific tasks of care, such as bathing, dressing, laundry, or housework caregivers are providing in the different categories of care.

Activities of Symptom Management Assistance Tasks of Care

The symptoms cancer patients experience as a result of the disease and treatment regimens impact the specific tasks of care caregivers provide. Some of the symptoms caregivers may need to provide assistance with include pain, nausea, or fatigue. Care task demands related to symptom assistance

are not included in the patient care categories for most studies.

Kurtz, Given, Kurtz, and Given (1994) focused on how patient age and stage of illness influences the frequency and severity of patients symptoms and dependencies in functioning. The study identified specific symptoms including nausea, pain, poor appetite, weight loss, fatigue, insomnia, constipation, diarrhea, and vomiting. Frequency and severity counts of 208 cancer patients' symptoms were obtained. The cancer diagnoses consisted of breast (24%), colorectal/gastrointestinal (21%), lung (16%), lymphoma (14%), urinary/reproductive (13%), head and neck (2%), and other (10%). Comparison of stages was accomplished by dividing the patients into three groups according to length of survival. Group I survived at least 12 months, Group II survived 6-12 months, and Group III survived less than 6 months. Patients with lung cancer constituted a large portion of Group II and III due to their increased mortality rates. The most frequently reported symptom was fatigue for all groups. The next four most frequently reported symptoms were pain, nausea, poor appetite, and constipation in various orders for the three groups. Symptoms proved to be a significant predictor of dependencies in activities of daily living and the need for caregiver assistance.

Mor, Masterson-Allen, Houts, and Siegel (1992) reported the prevalence of symptoms experienced by 629 patients with cancer during and three to six months after a course of

outpatient chemotherapy and/or radiation therapy. The sample consisted of patients with breast cancer (23%), lung cancer (22%), gastrointestinal cancer (20%), genitourinary cancer (20%), and other cancers (15%). More than half of the patients in the sample (54%) reported pain at baseline and 34% more of the patients identified new symptom experience of pain at follow-up. Nausea was identified by 37% of the patients at baseline and an additional 16% at follow-up. Diarrhea was reported by 27% of the patients at baseline and 13% developed symptoms of diarrhea at follow-up. Shortness of breath was reported by 27% of the patients at baseline with only 20% of the patients at follow-up reporting shortness of breath. Patients with metastatic disease were significantly more likely to have developed a new symptom need at follow-up than those patients with regional or local disease.

There are few studies that examine specific symptoms requiring assistance and management by caregivers. Both of these studies (Kurtz, Given, Kurtz, & Given, 1994; Mor, Masterson-Allen, Houts, & Siegel, 1992) also examined these activities of symptoms management in relation to stage of cancer. However, many different cancer diagnoses were represented and activities of symptom management were not identified for different diagnoses. This is a dimension of caregiver assistance that requires further exploration.

Activities of Health Care Assistance Tasks of Care

The treatments that patients are involved in as a result of the disease may require the assistance of caregiver in the home. Care task demands related to health care activities are not included in the patient care categories in most studies.

Oberst, Thomas, Gass, and Ward (1989) studied the caregiving demands of 47 family caregivers of patients with cancer receiving radiation treatment. The possible caregiving activities the caregivers could identify included transportation, emotional support, extra housework, managing illness-related finances/paperwork, structuring activities, monitoring/reporting symptoms, managing behavior, treatments, assisting with mobility, and personal care. The study was not specific about the type of symptoms, management behavior, or treatments required of caregivers. Cancer diagnosis and stage of disease were not provided. Inclusion criteria was only that the patient have a diagnosis of cancer and be receiving radiation therapy. The caregivers rated all but one of the patients illness as moderated to extremely serious. Caregiving demands were identified by measuring the time and energy expended in caregiving activities. The caregivers reported spending the most time giving emotional support, transportation, and increasing housework. Monitoring and/or reporting symptoms and providing medical/nursing treatments were reported as requiring a moderate amount of time. The least time was

spent on providing personal care to the patient and assisting with mobility.

Carey, Oberst, McCubbin, and Hughes (1991) studied 49 family caregivers who were caring for adult family members receiving outpatient chemotherapy. The cancer diagnoses consisted of breast (29%), gastrointestinal (18%), genitourinary (16%), lymphoma (14%), lung (8%) and other (14%). Most of the caregivers (92%) reported the illness to be moderately to extremely serious. The possible caregiver activities the caregivers could identify included 14 different categories. Some of activities included assisting with activities of daily living, instrumental activities of daily living, symptom monitoring and reporting, and providing medical/nursing treatments. The study was not specific about the type of symptom assistance, behavior management, or medical/nursing treatments required by the caregivers. The caregivers in this study reported providing assistance most frequently with instrumental activities of daily living, followed by the monitoring/reporting symptoms activity, and providing assistance with medical/nursing treatments. The least need for assistance reported by the caregivers was in the activities of daily living or personal care category.

These studies identified caregiving activities that involved activities of daily living, activities related to patient symptoms, and activities related to health care. Again, these caregiving activities of assisting with

activities of daily living, monitoring and/or reporting symptoms, and providing medical or nursing treatments were broad and did not describe the actual care provided, especially in the symptom and health care assistance activities. The information obtained from these studies provided an overview of the types or categories of caregiver assistance provided to patients with cancer. Further studies to determine more specific activities of care provided in these categories including the type of symptoms, such as pain control, management of nausea or constipation, and the type of health care assistance activities, such as wound or colostomy care, intravenous care, or assistance with medications requiring caregiver assistance would provide valuable information for health care providers caring for patients with cancer and their caregivers.

The cancer patients in these studies were receiving either radiation therapy or chemotherapy. Although it is important to understand the impact of treatments on the needs of patients with cancer, without information about the specific site of cancer and stage of disease it is difficult to identify the impact these factors may also have on the need for caregivers to provide assistance.

Site of Cancer and Tasks of Care

The site of cancer may influence the tasks of care provided by caregivers. Sarna (1994) studied the functional status of 69 women diagnosed with primary lung cancer within the previous 5 years. The disruptions in physical function

identified in the study included reduction in energy, difficulty with household chores, interferes with work, frequent pain, difficulty bending or lifting, difficulty planning activities, clothes didn't fit, food unappealing, cannot gain weight, and difficulty with self care. The most frequently reported disruption in physical function were reduced energy (59%), difficulty with household chores (33%), and interference with work (28%). The stage of disease was not reported, but the subjects needed to be physically well enough to report to data collection sites at a university medical center or private medical offices. This indicates that the effects of lung cancer decrease the patients physical stamina and their ability to maintain important activities in their life.

Sarna, Lindsey, Dean, Brecht, and McCorkle (1994) studied the relationship of weight change and lung cancer on symptom distress and functional status. Weight Loss is a common phenomenon related to advanced lung cancer. A sample of 60 patients with advanced disease were monitored for the pattern of weight change at five 6-week intervals beginning 2 months after diagnosis. Weight loss of 10% or more occurred in 35% of the subjects at study entry and almost half of the sample lost weight during the study. The sample reported that increased weight loss was associated with decreased function and increased symptom distress. Symptom distress was determined by utilizing cancer-related symptoms on the modified Symptom Distress Scale. Functional status

was measured with the revised Enforced Social Dependency Scale. The findings of this study indicate that weight loss is a frequently occurring symptom of patients with lung cancer that adversely effects other symptoms and functional ability. However, the study does not specifically identify those symptoms and functional abilities that are affected.

These studies of patients with lung cancer do not provide information about the specific care needed by patients and provided by caregivers. These studies do, however, identify that patients with lung cancer experience decreasing ability to perform activities of daily living and increasing symptom distress that may require caregiver assistance.

Studies specifically examining the care needs required by patients with colorectal cancer were non-existent. The bulk of the colorectal cancer research examines prevention and does not address care needs of the patient. However, most of the studies regarding care needs utilize cancer patients in general, which include patients with colorectal cancer. The information obtained by examining specific cancer diagnosis groups may identify different care needs and different caregiver assistance activities.

Stage of Cancer and Tasks of Care

The stage of illness can also impact the needs of cancer patients and their caregivers. Stetz (1987) described the caregiving demands of 65 patients with cancer in the terminal phase. The three most frequent diagnostic

categories were lung cancer in 31%, prostate cancer in 17%, and breast cancer in 11% of the patients. The patients' cancer was classified as either advanced stable (presence of metastatic disease or tumor progression beyond the original site in a patient whose condition was not changing or slightly improving) or as advanced progressive (presence of metastatic disease or tumor progression beyond the original site with progressive deterioration of the person's health). Only 5% of the study sample were classified as advanced stable, while 95% were classified as advanced progressive. The caregiver demands reported most frequently were managing the physical care, treatment regimen, and changes caused by the illness. This included assisting with activities of daily living and treatment and coping with changes in the patients physical and emotional status. However, this study did not identify the specific physical and emotional changes caused by the disease.

Houts et al. (1988) studied 433 persons with cancer in Pennsylvania during the period of terminal care. Family members or close friends identified unmet needs during the last month of life for patients with breast, lung and colon cancer. Activities of daily living was the most frequent unmet need according to 42% of the caregivers, followed by emotional and physical unmet needs at 21%. Activities of daily living included feeding and dressing self, walking, getting up or down stairs, preparing meals and doing home maintenance. Physical needs included nausea, fatigue, pain,

decreased sexual activity, bladder or bowel management, or changes in appearance. Home health care unmet needs were estimated to be less than 15% according to the caregivers. This category included learning to care for the patient with cancer at home, obtaining medical supplies at home, or getting medical help from community agencies or groups. The study also reported significantly more unmet needs during the terminal period compared to just after diagnosis in activities of daily living, obtaining health care, transportation, and problems with medical staff.

These studies (Stetz, 1987; Houts et al., 1988) examined the effect of late stage disease on the assistance activities of the caregiver and suggest that assistance with physical care increases with late stage disease. Activities of daily living, symptom assistance and health care assistance needs were included in the studies, but in general terms.

The studies regarding cancer caregiver assistance have focused most frequently on emotional aspects (Given, Stommel, Given, Osuch, Kurtz, & Kurtz, 1993; Tringali, 1986; Schumacher, Dodd, & Paul, 1993; Oberst & Scott, 1988; Blank, Clark, Longman, & Atwood, 1989) and to a lesser extent the physical requirements of the disease. Studies of physical care assistance focus on functional status and assistance with activities of daily living, but few studies have identified tasks of care related to the patient symptom experience or health care treatments required. The effects

of lung cancer on the functional status of the patient have been studied, but the tasks of care required by caregivers have not been specifically identified. Research regarding colorectal cancer and caregiver assistance is not available. Late stage cancer care has focused almost exclusively on the emotional impact on the caregiver including depression, burden, stressors, and role strain without examining the actual tasks of care that are also required of the caregiver at that time.

This study will identify the categories of care tasks most frequently requiring the assistance of caregivers for patients with late stage lung and colorectal cancer. Within these categories, the specific tasks of care can be identified to provide more information about what kinds of care the caregivers are actually providing. Finally, by focusing specifically on patients with late stage lung and colorectal cancer and their caregivers any differences can be identified and related to the particular disease.

METHODS

Research Design

The original study was an inception cohort of patients with cancer and their caregivers gathered in collaboration between Michigan State University (MSU) College of Nursing, College of Human Medicine, Departments of Family Practice, Medicine and Surgery, the Cancer Center at MSU, and the MSU Cancer Treatment Consortium. The Family Home Care for Cancer - A Community-Based Model, Grant #2 R01 NR/CA01915 is

funded by the National Institute of Nursing Research and the National Cancer Institute, Barbara A. Given, PhD, RN, FAAN, and Charles W. Given, PhD, Principal Investigators. A structured, closed-ended interview was conducted by phone with both the patient and the caregiver followed by a self-administered questionnaire used at multiple waves. A descriptive secondary analysis was performed on part of this data set.

Study Sample

The original study used a convenience sample of patient/caregiver dyads from 27 community cancer sites in Michigan. The eligibility criteria for entry in the study was as follows: adult patients over 65 years of age, a new diagnosis of either breast, colorectal, lung or prostate cancer, and currently undergoing some form of initial treatment beyond palliation for the disease. Each patient was asked to identify his or her primary caregiver.

The sample for this study used a sub-sample of 53 caregivers of patients with cancer. The eligibility criteria for entry in the study was as follows: caregivers of adult patients over 65 years of age with a new diagnosis of late stage lung cancer or late stage colorectal cancer.

Late stage lung cancer and colorectal cancer for the original study were determined by an audit of the patients chart at the original screening. Late stage lung cancer for this study includes stages IIIA, IIIB, and IV of the TNM staging system. This includes all tumor classifications

(T1-T4), metastasis in ipsilateral mediastinal and/or subcarinal lymph node(s) or metastasis in contralateral mediastinal, contralateral hilar, ipsilateral or contralateral scalene or supraclavicular lymph nodes (N2-N3), and the presence or absence of distant metastasis (M0-M1).

Late stage colorectal cancer includes stages III and IV of the TNM system, stage C and D of the Duke system, and stage C1, C2, C3, and D of the MAC system. This includes any primary tumor (T1-T4), metastasis to any regional lymph nodes (N1-N3), and the presence or absence of distant metastasis (M0-M1).

Data Collection Procedures

In the original study, after the initial screening information was obtained, both the patient and caregiver were contacted within six weeks by a trained interviewer and a phone interview was conducted lasting approximately 45 minutes to an hour. Follow-up continued at 12, 24, and 52 weeks. The patient and caregiver were interviewed individually and were asked different structured, closed-ended questions. The interview was followed up with mailed, self-administered questionnaires for the patient and the caregiver.

The interviewers were nurses or medical students who were provided with training, which included: a) mock interviews, b) taped interviews, and c) quality assurance assessments accomplished with 10% of the records reviewed

and monthly interviews to ensure that the research protocol was followed.

For this study, the patient's caregiver was the data source. The caregiver's first wave of phone interviews at 6-8 weeks after diagnosis was utilized to obtain the data needed. The questions centered around the caregivers perception of the patients need for assistance with tasks of care within the three categories (see Appendix A). The sociodemographic information was obtained from the patient's first wave of phone interviews at 6-8 weeks after diagnosis (see Appendix B).

Operational Definitions

The independent variable for this study was the site of cancer. The sites of cancer included: 1) late stage lung cancer, or 2) late stage colorectal cancer. Late stage cancer included: 1) stages III and IV of the TNM system, or 2) stages C and D of the Duke's system.

The dependent variables in this study included: 1) three categories of care, and 2) sub-categories of tasks of care within each category of care. The categories of care are defined as a group of several similar activities or tasks of care provided by caregivers for patients with cancer. The categories of care for this study have been divided into three groups of activities which include: 1) Activities of Daily Living/Instrumental Activities of Daily Living Assistance, 2) Activities of Symptom Management Assistance, and 3) Activities of Health Care Assistance.

The tasks of care are the specific activities within each category of care that are provided by caregivers for patients with cancer. The caregivers were asked to respond to whether assistance has been provided for the patient in each of the specific tasks of care within the three different categories of care.

The Activities of Daily Living/Instrumental Activities of Daily Living Assistance category consists of 11 tasks of care which include: dressing, bathing, eating, walking in house, toileting, transferring in/out of bed, transportation, laundry, shopping, housework, and cooking and preparing meals.

The Activities of Symptom Management Assistance category consist of 15 tasks of care which 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 frequently urination.

The Activities of Health Care Assistance category consists of 19 tasks of care which include: special exercise/physical therapy, oral medication, topical patch for pain management, injections, special intravenous medications/fluids, infusion pumps, tube feedings, mouth care, skin care, care of ulcers/bedsores, care of incision/wound or drainage tube, assistance because of incontinence of urine, urinary catheter/catheter care, ostomy care, constipation prevention, assistance because of

incontinence of stool, colostomy care, and testing of urine or stool.

The sociodemographic characteristics of the patient include: 1) age, 2) gender, 3) household income, and 4) living arrangements. Patient age was measured in years. Patient gender includes: 1) male, and 2) female. Patient household income includes the combined household income of all members: 1) <\$4,999, 2) \$5,000 - \$19,999, 3) \$20,000 - \$34,999, 4) \$35,000 - \$49,999, and 5) over \$50,000. Patient living arrangement will include: 1) caregiver lives with patient, and 2) caregiver and patient live in different households.

The sociodemographic characteristics of the caregiver include: 1) age, 2) gender, and 3) relationship to patient. Caregiver age was measured in years. Caregiver gender includes: 1) male, and 2) female. Caregiver relationship to the patient includes: 1) spouse, 2) daughter, 3) daughter-in-law, 4) son, 5) sister, and 6) other.

Measurement and Scoring

In the original Family Home Care for Cancer study, three scales were used to collect data from the caregivers regarding the specific tasks of care provided. These scales were the activities of daily living and instrumental activities of daily living, the activities of symptom assistance and the activities of health care assistance (see Appendix A).

The Activities of Daily Living/Instrumental Activities of Daily Living Assistance category were measured by having the caregiver respond to whether the patient was currently: 1) independent, 2) needed supervision only, 3) needed some physical help, or 4) needed total physical help in 11 tasks of care. For each task of care the responses were coded as "0" if the patient was independent, or "1" if the patient needed supervision only, needed some physical help or needed total physical help. Response items 2, 3, and 4 were grouped together to obtain consistent scoring with the other categories of care. Some form of assistance was provided by the caregiver in these responses, however, in different degrees which will not be examined in this study. The Activities of Daily Living category summated scale was on a score of 0-11.

The Activities of Symptom Management Assistance category were measured by having the caregiver respond to whether they or anyone else assisted the patient with a response of: 1) yes, or 2) no for 15 symptom assistance tasks of care. For each task of care the responses were coded as "0" if no assistance was required, or "1" if assistance was required. The Activities of Symptom Management Assistance summated scale was on a score of 0-15.

The Activities of Health Care Assistance category were measured by having the caregiver respond to whether the patient required 19 treatment or procedure tasks of care with a response of who helps: 1) you (primary caregiver), 2)

paid family, 3) paid friends/others, 4) paid professional, 5) unpaid family, 6) unpaid friends/others, or 7) unpaid professional. For each task of care the responses were coded "0" if no one helped, and "1" if one or more helped with a treatment or procedure needed. These responses may not be mutually exclusive resulting in the one caregiver being identified more than once. However, the purpose of this study was to identify specific tasks of care requiring assistance and was only scored once no matter how many caregivers provided assistance. The Activities of Health Care Assistance category summated scale was on a score of 0-19.

Data Analysis

For Research Question 1, to determine the most frequently occurring specific tasks of care needed by patients, a composite score was computed for each task of care identified. Percentages were computed based on the total sample, the group of caregivers for patients with lung cancer, and the group of caregivers for patients with colorectal cancer.

For Research Question 2, a summated score of all the tasks of care identified in each of the three categories were determined for the entire sample, the group of caregivers for patients with lung cancer, and the group of caregivers for patients with colorectal cancer. A mean and standard deviation of these summated scores for each of the three categories of tasks of care were determined for each

of the diagnosis groups. A T-test was applied to test for significant differences in the means of the three categories of care for patients with late stage lung and colorectal cancer.

Protection of Human Subjects

For the original study, patients were contacted initially while hospitalized and information about the study was presented to them by a staff member from the research project. Oncologists were informed of the study. Both the patient and primary caregiver needed to be willing to participate in the study. After both parties agreed, the patient signed a consent form (see Appendix C) and the caregiver signed a consent form (see Appendix D). Subjects could withdraw from the study at any time. They could also refuse to answer any questions. Subjects had the right to ask questions at any time.

The researcher protected the anonymity of the subjects by transcribing all data by code numbers. The only identifying information on the data is the code number. Only the principal investigators can track the patient. The consent forms and identifying data of each subject are not available to this researcher. The original study was approved by the University Committee on Research Involving Human Subjects at Michigan State University and is reviewed yearly while it is ongoing (see Appendix E).

Approval to conduct secondary analysis for this study was obtained from Michigan State University's Committee on

Research Involving Human Subjects prior to initiation of data analysis (see Appendix F). A sub-sample of the original sample was utilized for this study. Consent forms were obtained before the original study was initiated and are on file and only available to the principal investigators. Data from the caregiver's first wave of phone interviews at six weeks were utilized. The subjects were entered by identification numbers only and did not contain any subject identifiers. Potential risks to the subjects were not anticipated for this study because the data had already been collected. No additional time was requested from the subjects. The research and its results were not explained to the subjects individually unless requested, but may be published. Any publications that result from this analysis may not identify subjects individually, but may make reference to the group as a whole.

Research Limitations

The absence of a random sampling procedure and sample size were threats to the external validity of this study, and limits the generalizability to the target population. There also may exist a lack of representation of patients with cancer that have an inconsistent support system and were unable to identify a single primary care provider, therefore did not meet inclusion criterion.

Co-morbid health conditions that also influence the need for caregiver assistance were not obtained for this

study which possibly threatens the internal validity of this study. The original study did obtain this information, however, for the purpose of this study this information was not utilized. In addition, small cell cancer and non-small cell carcinoma were not identified for the patients with lung cancer in this study. Small-cell carcinoma has a much poorer prognosis with a potentially different level of caregiver assistance that was not indicated in this study.

Lack of information about the treatment regimen for this study limited interpretation of the results. Many of the patients in this study, 6-8 weeks after initial diagnosis, may have been recovering from surgery, as well as, being in the initial phase of receiving radiation and/or chemotherapy which would have provided valuable information related to the tasks of care requiring assistance at this point in the patients disease and treatment trajectory.

The different number of response items for the categories of care and lack of sample response in some categories of care threatens the internal consistency of the study. Each of the categories of care required different forms of responses from the caregivers in determining the assistance provided for the specific tasks of care. The Activities of Daily Living/Instrumental Activities of Daily Living Assistance category provided multiple choices in response to patient needs, while the Activities of Symptom Management Assistance category provided dichotomous responses, and the Activities of Health Care Assistance

category requested the caregiver identify who if anyone provided assistance to the patient. The multiple choice response provides more opportunity to express a range of views and an improved response rate. The dichotomous responses provided less opportunity to express an accurate response and may also have decreased the response rate.

The significant lack of responses in the Activities of Symptom Management Assistance category threatens the reliability of the study. The lack of responses in this category reduced the sample size for both groups of patients with cancer. It is impossible to determine whether the lack of response indicated no need in that area or a lack of understanding by the respondent regarding the questions being asked.

RESULTS

Description of the Sample

The sample consisted of 53 caregivers, with slightly more than half ($n = 29$, 55%) caring for patients with lung cancer, and 24 (45%) caring for patients with colorectal cancer. The mean age of the patients with lung cancer and colorectal cancer was 71 years ($SD = 4.84$) and 73 years ($SD = 6.86$), respectively (see Table 1). The caregivers of patients with lung cancer mean age of 59 years ($SD = 10.73$) was slightly younger, than the patients with colorectal cancer at 63 years ($SD = 10.43$). Stage of cancer for both groups was similar with almost two thirds (64%, $N = 34$) diagnosed with stage III cancer and slightly more than a

Table 1.

Demographic Characteristics of Caregivers and Patients by Site of Cancer

Characteristic	Lung Cancer (n = 29)		Colorectal Cancer (n = 24)		Total (n = 53)	
	X	(SD)	X	(SD)	X	(SD)
Age (years)						
Patient Age	71	4.84	73	6.86		
Caregiver Age	59	10.73	63	10.43		
	Lung Cancer		Colorectal Cancer		Total	
	n	(%)	n	(%)	n	(%)
Stage of Cancer						
Stage III	18	(62.1)	16	(66.7)	34	(64.2)
Stage IV	11	(37.9)	8	(33.3)	19	(35.8)
Patient Gender						
Male	17	(58.6)	8	(33.3)	25	(47.2)
Female	12	(41.4)	16	(66.7)	28	(52.8)
Caregiver Gender						
Male	3	(15.8)	6	(30.0)	9	(23.0)
Female	16	(84.2)	14	(70.0)	30	(77.0)
Caregiver Relationship to Patient						
Spouse	24	(82.8)	16	(66.7)	40	(75.5)
Daughter	2	(6.9)	3	(12.5)	5	(9.4)
Daughter-in-Law	1	(3.4)	2	(8.3)	3	(5.7)
Sister	0	(0.0)	1	(4.2)	1	(1.9)
Son	1	(3.4)	0	(0.0)	1	(1.9)
Other	1	(3.4)	2	(8.3)	3	(5.7)
Caregiver Lives with Patient						
Yes	15	(71.4)	7	(58.3)	22	(66.7)
No	5	(23.8)	3	(25.0)	8	(24.2)
No answer	1	(3.4)	2	(16.7)	3	(9.1)
Household Income						
\$5,000-\$19,999	10	(55.5)	7	(63.6)	17	(58.6)
\$20,000-\$34,999	6	(33.3)	2	(18.2)	8	(27.6)
\$35,000-\$49,999	2	(11.1)	2	(18.2)	4	(13.8)

third (36%, $N = 19$) diagnosed with stage IV cancer.

Slightly more than half (59%, $n = 17$) of the patients with lung cancer were male, while two thirds (67%, $n = 16$) of the patients with colorectal cancer were female. More than three fourths (77%, $N = 30$) of the caregivers were female for the total sample.

More than three fourths (76%, $N = 40$) of the caregivers were spouses, with more spouses caring for patients with lung cancer (83%, $n = 24$) than spouses caring for patients with colorectal cancer (67%, $n = 16$). Two thirds of the total sample were living with the patients (67%, $n = 22$). More patients with lung cancer live with the caregiver (71%, $n = 14$) than patients with colorectal cancer (58%, $n = 7$). This difference was statistically significant, $t(33) = 4.115$, $p = .051$. The household income reported was less than \$20,000 for more than half (59%, $n = 17$) of both caregivers of patients with lung cancer and colorectal cancer. None of the caregivers for patients with lung or colorectal cancer reported an income over \$50,000.

Answers to Research Questions

(1) Within each of the three categories of care, which are the most frequently occurring specific tasks of care that patients with late stage lung and colorectal cancer require assistance as reported by caregivers?

In the category of Activities of Daily Living/ Instrumental Activities of Daily Living Assistance, caregivers reported that patients with lung cancer required

the most assistance with transportation (59%, $n = 17$), housework (52%, $n = 15$), and cooking/preparing meals (48%, $n = 14$) represented in Table 2. The caregivers reported that patients with colorectal cancer required the most assistance in this category with transportations (50%, $n = 12$), housework (46%, $n = 11$), and shopping (38%, $n = 9$). The percentage of caregivers reporting no assistance required in this category were 24% ($n = 7$) for the patients with lung cancer and 29% ($n = 7$) for the patients with colorectal cancer. The non-response rate occurred more frequently with the caregivers of patients with lung cancer (10%, $n = 31$) than with the caregivers of patients with colorectal cancer (5%, $n = 13$). The non-responses occurred in all of the Instrumental Activities of Daily Living Assistance, which were the activities identified by the caregivers as needing the most assistance.

In the category of Activities of Symptom Management Assistance, the caregivers reported that patients with lung cancer required the most assistance with poor appetite (35%, $n = 7$), pain (35%, $n = 7$), and weight loss (25%, $n = 5$) represented in Table 2. The caregivers reported that patients with colorectal cancer required the most frequent assistance with poor appetite (42%, $n = 5$), pain (42%, $n = 5$), weight loss (33%, $n = 4$), fatigue (33%, $n = 4$), and diarrhea (33%, $n = 4$). Caregivers of patients with colorectal cancer reported a significantly higher frequency of need for assistance with fatigue, $t(32) = 23.89$, $p =$

Table 2.

Frequencies and Percentages of Specific Tasks within Care Categories by Site of Cancer

Specific Tasks of Care Activities of Daily Living/ Instrumental Activities	Lung Cancer (n = 29)		Colorectal Cancer (n = 24)		Total (n = 53)	
	n	(%)	n	(%)	n	(%)
Transportation	17	(58.6)	12	(50.0)	29	(54.7)
Housework	15	(51.7)	11	(45.8)	26	(49.1)
Cooking/Preparing Meals	14	(48.3)	8	(33.3)	22	(41.5)
Shopping	11	(37.9)	9	(37.5)	20	(37.7)
Laundry	9	(31.0)	7	(29.2)	16	(30.2)
Bathing	6	(20.7)	5	(20.8)	11	(20.8)
Dressing	3	(10.3)	3	(12.5)	6	(11.3)
Walking in House	3	(10.3)	1	(4.2)	4	(7.5)
Toileting	2	(6.9)	0	(0.0)	2	(3.8)
Transferring In/Out of Bed	2	(6.9)	0	(0.0)	2	(3.8)
Eating	0	(0.0)	0	(0.0)	0	(0.0)
No Assistance Needed	7	(24.1)	7	(29.2)	14	(26.4)
Non-Responses	31	(9.7)	13	(4.9)	44	(7.5)

Activities of Symptom Management Assistance

Specific Tasks of Care Activities of Symptom Mgmt	Lung Cancer (n = 20)		Colorectal Cancer (n=12)		Total (n = 32)	
	n	(%)	n	(%)	n	(%)
Poor Appetite	7	(35.0)	5	(41.6)	12	(37.5)
Pain	7	(35.0)	5	(41.6)	12	(37.5)
Weight Loss	5	(25.0)	4	(33.3)	9	(28.1)
Nausea	4	(20.0)	2	(16.6)	6	(18.8)
Dry Mouth	4	(20.0)	2	(16.6)	6	(18.8)
Fatigue	1	(5.0)	4	(33.3)	5	(15.6)
Trouble Sleeping	3	(15.0)	2	(16.6)	5	(15.6)
Vomiting	3	(15.0)	1	(8.3)	4	(12.5)
Coordination Problems	1	(5.0)	3	(25.0)	4	(12.5)
Diarrhea	0	(0.0)	4	(33.3)	4	(12.5)
Constipation	2	(10.0)	2	(16.6)	4	(12.5)
Difficulty Breathing/SOB	3	(15.0)	0	(0.0)	3	(9.4)
Fever	1	(5.0)	0	(0.0)	1	(3.1)
Frequent Urination	1	(5.0)	0	(0.0)	1	(3.1)
Cough	1	(5.0)	0	(0.0)	1	(3.1)
No Assistance Needed	5	(25.0)	4	(33.3)	9	(28.1)
Non-Responses	159	(53.0)	93	(51.7)	252	(52.5)

Table 2 (cont.)

Specific Tasks of Care	Lung Cancer (n = 29)		Colorectal Cancer (n = 24)		Total (n = 53)	
Activities of Health Care	n	(%)	n	(%)	n	(%)
Oral Medications	24	(82.8)	14	(58.3)	38	(71.7)
Constipation Prevention	4	(13.8)	6	(25.0)	10	(18.9)
Skin Care	3	(10.3)	5	(20.8)	8	(15.1)
Colostomy Care	0	(0.0)	7	(29.2)	7	(13.2)
Special IV Access	2	(6.9)	5	(20.8)	7	(13.2)
Care of Incision/Wound	3	(10.3)	2	(8.3)	5	(9.4)
IV Medications/Fluids	2	(6.9)	2	(8.3)	4	(7.5)
Mouth Care	1	(3.4)	3	(12.5)	4	(7.5)
Physical Therapy	2	(6.9)	2	(8.3)	4	(7.5)
Testing of Urine or Stool	2	(6.9)	1	(4.2)	3	(5.7)
Stool Incontinence	1	(3.4)	2	(8.3)	3	(5.7)
Infusion Pumps	1	(3.4)	1	(4.2)	2	(3.8)
Topical Patch Pain Mgmt	2	(6.9)	0	(0.0)	2	(3.8)
Injections	1	(3.4)	0	(0.0)	1	(1.9)
Urinary Incontinence	1	(3.4)	0	(0.0)	1	(1.9)
Urinary Catheter Care	1	(3.4)	0	(0.0)	1	(1.9)
No Assistance Needed	3	(10.3)	2	(8.3)	5	(9.4)
Non-Responses	3	(10.3)	3	(12.5)	6	(11.3)

000, and diarrhea, $t(32) = 7.11$, $p = .029$, than the caregivers of patients with lung cancer. The percentage of caregivers reporting no assistance required in this category was 25% ($n = 5$) for patients with lung cancer and 33% ($n = 4$) for the patients with colorectal cancer. The non-response rate in the Activities of Symptom Management Assistance category was high for both groups of caregivers. Caregivers of patients with lung cancer did not respond to 53% ($n = 159$) of the specific tasks of care and the caregivers of patients with colorectal cancer did not respond to 52% ($n = 93$) of the specific tasks of care. The caregivers that did not respond to any of the items in this

category were eliminated resulting in a reduced sample size of 20 caregivers for patients with lung cancer and 12 caregivers for patients with colorectal cancer.

In the category of Activities of Health Care Assistance, caregivers reported that patients with lung cancer most frequently required assistance with oral medications (83%, $n = 24$), constipation prevention (14%, $n = 4$), skin care (10%, $n = 3$), and care of incision/wound (10%, $n = 3$) represented in Table 2. Caregivers of patients with colorectal cancer in this category reported providing assistance most frequently with oral medications (58%, $n = 14$), colostomy care (29%, $n = 7$), and constipation prevention (25%, $n = 6$). Caregivers of patients with lung cancer identified a significantly higher frequency of need for assistance with oral medications than the caregivers of patients with colorectal cancer, $t(53) = 13.92$, $p = .000$. The caregivers of patients with colorectal cancer reported a statistically significantly higher frequency of need for assistance with colostomy care than the caregivers of patients with lung cancer, $t(53) = 132.83$, $p = .000$. The percentage of caregivers reporting no assistance required in this category was 10% ($n = 3$) for patients with lung cancer and 8% ($n = 2$) for patients with colorectal cancer. The non-response rate in this category of care was very low. Caregivers of patients with lung cancer did not respond to 10% ($n = 3$) of the specific tasks of care and caregivers of

patients with colorectal cancer did not respond to 13% ($n = 3$) of the specific tasks of care.

The specific tasks of care requiring assistance by patients with lung and colorectal cancer were similar in all three categories of care. In the Activities of Daily Living Assistance category, both groups of caregivers reported assisting most frequently with transportation and housework. In the Activities of Symptom Management Assistance category, both groups of caregivers reported assisting most frequently with poor appetite and pain. In the Activities of Health Care Assistance category, both groups of caregivers reported assisting most frequently with oral medications and constipation prevention. Caregivers of patients with colorectal cancer also frequently reported assisting with colostomy care in this category.

(2) Are there differences between patients with late stage lung cancer and colorectal cancer in the average number of specific tasks of care for which assistance was required as reported by caregivers in each of the three categories of care?

In the Activities of Daily Living/Instrumental Activities of Daily Living Assistance category, the caregivers for patients with lung cancer reported assisting with more specific tasks of care in this category ($M = 2.8$, $S.D. = 2.90$), than the caregivers for patients with colorectal cancer ($M = 2.3$, $S.D. = 2.50$) as represented in

Table 3. However, the difference was not statistically significant, $t(53) = .412$, $p = .524$.

In the Activities of Symptom Management Assistance, the caregivers for patients with lung cancer reported providing assistance with fewer specific tasks of care in this category ($M = 2.2$, $S.D. = 2.17$), compared to the caregivers for patients with colorectal cancer ($M = 2.8$, $S.D. = 2.37$) as represented in Table 3. The difference was not statistically significant, $t(32) = .191$, $p = .849$. Several of the caregivers did not respond to any of the items in this category, therefore the sample in this category is reduced to 20 caregivers for patients with lung cancer and 12 caregivers for patients with colorectal cancer.

In the Activities of Health Care Assistance, the caregivers for patients with lung cancer reported providing assistance with fewer specific tasks of care ($M = 1.7$, $S.D. = 1.19$), than the caregivers for patients with colorectal cancer ($M = 2.1$, $S.D. = 1.25$) as represented in Table 3. However, the difference was not statistically significant, $t(53) = .117$, $p = .734$.

The standard deviations for all of the categories of care were large. The range in the number of specific tasks of care needing assistance as reported by the caregivers was wide (see Table 4). Most of the caregivers reported zero to four specific tasks of care needing assistance, however there were also some caregivers reporting seven or more needs for assistance in the Activities of Daily

Table 3.

Means and Standard Deviations of Categories of Tasks of Care by Site of Cancer

Categories of Tasks of Care	Lung Cancer n = 29 Mean (SD)	Colorectal Cancer n = 24 Mean (SD)	Total n = 53 Mean (SD)	Statistic t	p Value
Daily Living Assistance	2.8 (2.90)	2.3 (2.50)	2.6 (2.71)	.412	.524
Symptom Assistance	2.2 (2.17)	2.8 (2.37)	2.5 (2.27)	.191	.849
Health Care Assistance	1.7 (1.19)	2.1 (1.25)	1.9 (1.25)	.117	.734

*In the Activities of Symptom Management Assistance, n = 20 for lung cancer and n = 12 for colorectal cancer.

Table 4.

Frequencies of Number of Specific Tasks of Care Reported by Category of Care

Number of Specific Tasks	Lung Cancer n = 29		Colorectal Cancer n = 24		Total n = 53	
ADL/IADL	n	(%)	n	(%)	n	(%)
0	7	(24.1)	7	(29.7)	14	(26.4)
1	6	(20.7)	6	(25.0)	12	(22.6)
2	4	(13.8)	2	(8.3)	6	(11.3)
3	2	(6.9)	2	(8.3)	4	(7.5)
4	2	(6.9)	1	(4.2)	3	(5.7)
5	3	(10.3)	1	(4.2)	4	(7.5)
6	2	(6.9)	2	(8.3)	4	(7.5)
7	1	(3.4)	0	(0.0)	1	(1.9)
8	0	(0.0)	2	(8.3)	2	(3.8)
9	0	(0.0)	0	(0.0)	0	(0.0)
10	2	(6.9)	1	(4.2)	3	(5.7)
11	0	(0.0)	0	(0.0)	0	(0.0)

(No more than 10 specific tasks were identified as needing assistance in this category)

Table 4 (cont.)

Number of Specific Tasks	Lung Cancer n = 29		Colorectal Cancer n = 24		Total n = 53	
Symptom Assistance	n	(%)	n	(%)	n	(%)
0	5	(25.0)	4	(33.3)	9	(28.1)
1	4	(20.0)	1	(8.3)	5	(15.6)
2	4	(20.0)	1	(8.3)	5	(15.6)
3	4	(20.0)	1	(8.3)	5	(15.6)
4	1	(5.0)	2	(16.7)	3	(9.4)
5	0	(0.0)	1	(8.3)	1	(3.1)
6	1	(5.0)	0	(0.0)	1	(3.1)
7	0	(0.0)	1	(8.3)	1	(3.1)
8	0	(0.0)	1	(8.3)	1	(3.1)
9	1	(5.0)	0	(0.0)	1	(3.1)
10	0	(0.0)	0	(0.0)	0	(0.0)

(No more than 9 specific tasks were identified as needing assistance in this category)

Numbers of Specific Tasks	Lung Cancer n = 29		Colorectal Cancer n = 24		Total n = 53	
Health Care Assistance	n	(%)	n	(%)	n	(%)
0	3	(10.3)	2	(4.2)	5	(9.4)
1	12	(41.4)	7	(29.2)	19	(35.8)
2	8	(27.6)	6	(25.0)	14	(26.4)
3	3	(10.3)	5	(20.8)	8	(15.1)
4	3	(10.3)	4	(16.7)	7	(13.2)

(No more than 4 specific tasks were identified as needing assistance in this category)

Living/Instrumental Activities of Daily Living Assistance and the Activities of Symptom Management Assistance categories. The Activities of Health Care Assistance category had smaller standard deviations related to all of the caregivers reporting only zero to four specific tasks of care requiring assistance.

There were differences in the average number of specific tasks of care requiring assistance by caregivers in all three categories of care. However, the differences were

not statistically significant. The caregivers of patients with lung cancer reported providing assistance with the greatest number of specific tasks of care in the Activities of Daily Living/Instrumental Activities of Daily Living Assistance category, followed by the Activities of Symptom Management Assistance, and with the least number of specific tasks of care in the Activities of Health Care Assistance. The caregivers of patients with colorectal cancer reported providing assistance with the greatest number of specific tasks of care in the Activities of Symptom Management Assistance, followed by the Activities of Daily Living/Instrumental Activities of Daily Living Assistance, and with the least number of tasks of care in the Activities of Health Care Assistance. The caregivers for patients with lung cancer reported needing more assistance with the Activities of Daily Living/Instrumental Activities of Daily Living Assistance than the caregivers of the patients with colorectal cancer. However, the caregivers for patients with colorectal cancer reported needing more assistance with the Activities of Symptom Management Assistance and the Activities of Health Care Assistance than the caregivers for patients with lung cancer.

DISCUSSION

Sample

In this descriptive study, a total of 53 caregivers for cancer patients were surveyed to identify tasks of care, within three broad categories, needed by patients with late

stage lung and colorectal cancer. Twenty-nine caregivers in the sample provided assistance to patients with lung cancer and 24 caregivers provided assistance to patients with colorectal cancer. Most of the caregivers for both groups of cancer patients were female, average age of 61 years. This is consistent with the literature (Given & Given, 1995; Olson, 1989), indicating that most often the family caregiver for patients with cancer is a female over 55 years of age. Most of the caregivers were spouses, followed by daughters, or daughter-in-laws. This is also consistent with the literature (Given & Given, 1995; Lewis, Woods, Hough & Bensley, 1989; Northouse, 1989), finding that when a spouse is not available to provide care, generally another family member, usually a daughter or daughter-in-law provides the care.

Two thirds of the caregivers and patients in the overall sample lived together. Significantly more patients with lung cancer and their caregivers lived together than patients with colorectal cancer and their caregivers. This may be explained by the difference in age of the two cancer groups. The patients with lung cancer and their caregivers were slightly younger and more of the caregivers were spouses than the patients with colorectal cancer and their caregivers. Spouses care for middle-aged adult patients in most cases (Lewis et al., 1989; Given & Given, 1991), however older cancer patients are more likely to be cared for by adult children. The patients with colorectal cancer

in this study, being slightly older were more frequently cared for by adult children and in these situations living arrangements may be changed temporarily to best manage the care, however living together permanently is not as likely.

No other significant demographic findings were identified between the patients with lung and colorectal cancer. The patients with lung cancer were slightly younger at an average of 71 years, than the patients with colorectal cancer at an average age of 73 years. This is interesting to note, especially since the criterion for this study was that the patients be 65 years or older. These findings are consistent with findings that smokers lose an average of 15 years of life, which is the most important risk factor in the development of lung cancer (American Cancer Society, 1997). The age of the of patients with colorectal cancer is also consistent with the finding of the American Cancer Society (1997) indicating that 62% of colorectal cancer are diagnosed between the ages of 60-79 with mean age of 72.9 years.

The combined household income of more than half of the caregivers for patients with lung and colorectal cancer was below \$20,000 and none had an income over \$50,000. This indicates that most of the caregivers and patients in this sample have low or very limited economic resources. Many of the caregivers may be retired. However, the age of the caregivers also indicates that some may still be employed outside of the home to maintain economic security for the

family while providing for the additional expenses of cancer care. Perry and Roades de Meneses (1989) identified that 50% of caregivers assisting a family member with cancer had a hard time maintaining their work schedule. Lost work hours due to caring for patients with cancer can severely impact the economic security of the patient and caregiver. In addition, the family is not able to hire additional help with the care that is required due to the high cost of these services.

The demographic characteristics of the overall sample are consistent with the literature describing lung and colorectal cancer populations. The overall sample of patients consisted of close to equal percentages of males and females. More than two thirds of the male patients had lung cancer compared to males with colorectal cancer. This is consistent with the findings of the American Cancer Society (1997) that indicate that lung cancer is more prevalent in males followed by colorectal cancer. However, for female patients there was a slightly higher percentage with colorectal cancer than lung cancer. This could possibly be explained by the fact that as the age of the female increases, the probability of developing lung cancer (3.8%) or colorectal cancer (3.2%) is almost equal (American Cancer Society, 1997), resulting in more female patients with colorectal cancer than lung cancer in this study.

Frequency Activities of Daily Living/Instrumental Activities of Daily Living Assistance Required

The specific tasks in the category of Activities of Daily Living/Instrumental Activities of Daily Living Assistance requiring the most frequent assistance reported by the caregivers in this study were transportation, housework, cooking/preparing meals, and shopping. All of the instrumental activities of daily living were identified by the caregivers as more frequently needing assistance compared to the self-care activities in this category of care.

The patients were in the initial phase of treatment in this study, which may explain the greatest needs being instrumental activities versus personal care activities. The demands for care change over time in response to the stage of the disease and phase in the treatment plan (Given & Given, 1995). Mor et al. (1987) found that patient need was related to the duration of the disease and pain. The initial phase of treatment frequently includes surgery, followed by radiation and/or chemotherapy. Surgery requires a period of rehabilitation with reduced energy and stamina requiring assistance with activities of long duration and higher energy levels, such as housework, shopping and cooking. Radiation treatments or chemotherapy require cancer patients to travel frequently, explaining the need for frequent assistance with transportation. However, due to the early phase of the disease and treatment, most

patients have not yet become debilitated from the effects of the disease, and are instead responding to the effects of the treatment. If the disease progresses causing further debilitation of the patient, it is more likely to require the assistance of the caregiver in personal care activities.

The literature is consistent in identifying instrumental activities of daily living as frequently requiring assistance by patients with cancer during the treatment phase of the disease. In a study of cancer patients receiving radiation therapy (Oberst, Thomas, Gass & Ward, 1989), caregivers reported spending most time providing transportation and increased housework. In a similar study conducted with cancer patients receiving chemotherapy (Carey, Oberst, McCubbin & Hughes, 1991), caregivers again identified spending most time providing transportation and increased housework. Similarly, household needs were identified more frequently by cancer caregivers than physical assistance needs or assistance with self-care needs of the patient (Wingate & Lackey, 1989; Hileman & Lackey, 1990).

In comparing the need for assistance in the Activities of Daily Living/Instrumental Activities of Daily Living Assistance category for patients with lung cancer and colorectal cancer, there were no significant differences. However, the caregivers of patients with lung cancer reported providing assistance with all of the specific tasks of care more frequently than the caregivers of the patients

with colorectal cancer. This indicates that the patients with lung cancer are more functionally debilitated than the patients with colorectal cancer. There were also slightly more stage IV patients with lung cancer than stage IV patients with colorectal cancer. Surgery may be a factor in the greater need for assistance of the patients with lung cancer, but information about specific treatments was not utilized for this study. The findings are consistent with the poor survival rate of patients with lung cancer, especially when diagnosed with late stage lung cancer compared to patients with late stage colorectal cancer (American Cancer Society, 1997).

These findings indicate that patients with lung cancer and colorectal cancer depend on their caregivers to provide assistance with many instrumental activities of daily living, especially transportation, housework and cooking/preparing meals. Patients with lung cancer require the assistance of their caregivers with these activities more frequently than patients with colorectal cancer. Personal care tasks, such as bathing and dressing, were not reported frequently by the caregivers in this study for either groups of patient with cancer. In the early phase of disease and treatment both the patients with lung cancer and colorectal cancer are still functionally able to perform their own personal care, but require assistance with transportation and household needs.

**Frequency Activities of Symptom Management Assistance
Required**

In the category of Symptom Management Assistance there was greater diversity in the specific tasks of care requiring assistance by the caregivers. Caregivers of patients with lung cancer reported assisting patients most frequently with symptoms of poor appetite, pain, and weight loss. Caregivers of patients with colorectal cancer reported assisting patients most frequently with symptoms of poor appetite, pain, weight loss, fatigue, and diarrhea. More of the caregivers of patients with colorectal cancer reported providing assistance with more of the tasks of care in this category than the caregivers of patients with lung cancer. In addition, the caregivers of patients with colorectal cancer identified providing assistance with symptoms of fatigue and diarrhea as frequently as assisting with symptoms of weight loss.

The effects of the treatment regimen on the patient in the initial phase of treatment may impact the patients need for assistance with these symptoms. During the post-surgical rehabilitation period the patient is weak and painful. Loss of appetite and weight loss are common during this period. In addition, the effects of radiation therapy and/or chemotherapy are poor appetite, weight loss, and fatigue.

Collectively, both caregivers of patients with lung cancer and colorectal cancer identified poor appetite and weight loss as two of the specific tasks of care requiring assistance most frequently. Weight loss is a common problem related to advanced cancer (Chlebowski, 1991; Lindsey, 1993). Patients with late stage cancer have frequently lost a significant amount of weight prior to being diagnosed. The subsequent treatment of surgery, radiation, and/or chemotherapy that occurs in the initial phase of cancer further complicates the symptoms of weight loss and poor appetite. There are several studies providing evidence supporting the association between weight loss and subsequent functional decline (Fayers, Bleehen, Girling, & Stephens, 1991; Sarna, Lindsey, Dean, Brecht, & McCorkle, 1994). The effects of poor appetite and weight loss for the patients in this study resulted in frequent caregiver assistance with these symptoms, as well as, the need to assist with preparing/cooking meals related to the patients decreased functional ability to do so independently.

Both groups of caregivers identified needing to provide assistance with pain frequently. Studies regarding pain management have indicated that it causes difficult problems for caregivers to manage (Blank et al., 1989; Ferrell, Rhiner, Cohen, Grant, & Rozek, 1991; Ferrell, Wenzl & Wisdom, 1988; Ferrell, Wisdom, & Scheneider, 1989; Hull, 1989). Kurtz et al. (1994) reported that the prevalence of selected symptoms, such as, pain, poor appetite, and weight

loss increased steadily with patients that were closer to death. Tumor impingement, obstruction in the abdomen, or metastatic pain to another area of the body relate to the late stage of the disease for the patients in this study and may explain the need for frequent assistance by caregivers in the management of pain. Surgery is the most likely treatment that would result in pain for the patients in the study.

The symptom of fatigue was reported at a significantly higher frequency of need by the caregivers of patients with colorectal cancer. This finding is consistent with the findings of Kurtz et al. (1994) which reported the symptom of fatigue occurring most frequently for patients with cancer. The symptom of fatigue being more prevalent for patients with colorectal cancer than patients with lung cancer is inconsistent, however, with the findings in the Activities of Daily Living Assistance category indicating that patients with colorectal cancer were more physically independent than patients with lung cancer in the instrumental activities requiring energy and stamina to perform. This may be due to many of the patients with lung cancer not having surgery because of the advanced state of the disease resulting in less initial fatigue. However, since surgery is the primary treatment for patients with colorectal cancer even in the advanced stages of the disease, it is likely that more of the patients with colorectal cancer in this study had surgery than the

patients with lung cancer resulting in more initial fatigue. In addition, fatigue is a common side effect of radiation therapy, but does not occur until a few weeks after it has been initiated.

Caregivers of patients with colorectal cancer also identified needing assistance with diarrhea significantly more than the caregivers of patients with lung cancer. The location of the disease and treatment required, especially surgery with the potential for a temporary or permanent colostomy, may influence this need. Radiation therapy in the gastrointestinal area can also cause diarrhea requiring more need for assistance with this symptom for patients with colorectal cancer.

Lung cancer caregivers reported a higher percentage of assistance, although not significant, with symptoms of coughing and difficulty breathing which is consistent with the diagnosis of lung cancer. These symptoms have the potential to cause fatigue for these patients. None of the patients with colorectal cancer reported needing assistance with either coughing or difficulty breathing.

The findings of this study indicate that in the Activities of Symptom Management Assistance, both the caregivers of patients with lung cancer and colorectal cancer identified the same specific tasks of care occurring most frequently. In addition, caregivers of patients with colorectal cancer reported providing assistance with the symptoms of fatigue and diarrhea with the same frequency as

the symptom of weight loss. The symptoms of poor appetite, weight loss, and pain may be related to the initial phase of treatment, especially surgery. The late stage of disease and extensive disease progression also impacts the extent of need with these symptoms. The caregivers of patients with colorectal cancer identified needing assistance with these tasks of care more often than the caregivers of patients with lung cancer indicating that more of the patients with colorectal cancer were experiencing these symptoms or were less physically able to manage them without caregiver assistance.

Frequency of Activities of Health Care Assistance Required

In the Activities of Health Care Assistance category, caregivers of patients with lung cancer reported assistance being required most frequently with administration of oral medications, constipation prevention, and wound and skin care activities. Caregivers of patients with colorectal cancer reported assistance being required most frequently with administration of oral medications, colostomy care, and constipation prevention in this category of care.

Overall, both groups identified oral medication administration as needing assistance much more frequently than any other Activity of Health Care Assistance. However, caregivers of patients with lung cancer identified a significantly higher frequency of need for assistance with oral medication than caregivers of patients with colorectal cancer. In general, patients with cancer require several

oral medications related to the treatment of the disease and the side effects of the treatment, including pain and nausea. Mor et al. (1992) reported that 53% of patients experience pain during active treatment. Ferrell et al. (1993) indicated that patients and caregivers must make many decisions and handle many problems regarding medications. The significantly greater need for assistance with oral medications for patients with lung cancer may indicate that they were experiencing more symptoms requiring oral medications or that the patients with lung cancer were less physically and/or mentally able to manage the administration of medications without assistance.

Constipation prevention activities were also frequently reported by both caregivers of patients with lung and colorectal cancer as needing assistance. The effect of the disease and treatment, especially surgery in the initial phase of treatment may influence this need. The patients with colorectal cancer required assistance more frequently with this task of care than the patients with lung cancer. This may be explained by the location of the cancer effecting the gastrointestinal area more profoundly than patients with lung cancer. The late stage of the disease implies that both groups of patients may have more pain requiring pain medication and decreased mobility resulting in further complicating the problem of constipation.

Caregivers of patients with lung cancer reported providing assistance with skin care and wound care with the

same frequency. The skin in the area treated by radiation therapy may become red, dry, tender, and itchy (National Cancer Institute, 1994). It is important for patients to take good care of their skin during treatment, which may require the assistance of the caregiver. In advanced disease, the need for skin care increases related to the patients immobility. Rapid deterioration in health and physical functional ability is characteristic of the patient with late stage lung cancer which may explain the greater need for assistance with skin and wound care compared to patients with colorectal cancer.

Caregivers of patients with colorectal cancer indicated frequently providing assistance with colostomy care. This need for assistance was significantly higher for patients with colorectal cancer than patients with lung cancer, which is consistent with the diagnosis of colorectal cancer. Although, the percentage of patients with colorectal cancer requiring a permanent colostomy is only 15%, a temporary colostomy is sometimes needed (American Cancer Society, 1997). Oberst and Scott (1988) reported that cancer patients with ostomies were slower to return to pre-illness functional levels than non-ostomy cancer patients. The impact for the patient and caregiver on those that do have a colostomy is evident.

This study indicates that in the Activities of Health Care Assistance category both the caregivers of patients with lung cancer and colorectal cancer provided assistance

with oral medications significantly more frequently than any of the other tasks of care in this category. The initial phase of treatment to manage the disease and control the side effects may influence this need. Significantly more of the patients with lung cancer required assistance with this task than patients with colorectal cancer possibly due to a more rapid decline of patients with lung cancer that has been documented (American Cancer Society, 1997).

Constipation prevention was also a frequently occurring task of care requiring assistance for both patients with lung and colorectal cancer. Patients with colorectal cancer required assistance with this task of care more frequently than patients with lung cancer related to the location of the disease and treatment required. Colostomy care assistance was frequently identified by caregivers for patients with colorectal cancer as might be expected.

Overall, the specific tasks of care requiring caregiver assistance in each of the three broad categories of care were very similar for patients with lung cancer and colorectal cancer. This indicates that in patients with late stage lung cancer and colorectal cancer in the initial phase of treatment there are similar needs for assistance. However, there were a few specific tasks of care requiring assistance based on the differences in the site of cancer. Specifically, patients with lung cancer had a much greater need for assistance with oral medications, while patients with colorectal cancer required greater assistance with

colostomy care. This indicates that site of cancer in advanced disease in the early phase of treatment may require specific needs for assistance by the caregiver, as well as, the more general needs of both groups of patients.

Frequency of Need in the Three Broad Categories of Care

Caregivers for patients with lung cancer reported providing the most assistance in the Activities of Daily Living/Instrumental Activities of Daily Living Assistance category, followed by the Activities of Symptom Management Assistance category, and last the Activities of Health Care Assistance category. The caregivers for patients with colorectal cancer reported providing the most assistance in the Activities of Symptom Management Assistance, followed by the Activities of Daily Living/Instrumental Activities of Daily Living Assistance, and last the Activities of Health Care Assistance. The caregivers for patients with lung cancer reported providing assistance in the Activities of Daily Living/Instrumental Activities of Daily Living Assistance more frequently than caregivers for patients with colorectal cancer. Caregivers for patients with colorectal cancer reported providing assistance in the Activities of Symptom Management Assistance and Activities of Health Care Assistance more frequently than caregivers for patients with lung cancer.

In the Activities of Daily Living/Instrumental Activities of Daily Living Assistance category, the caregivers for patients with lung cancer reported greater

need in all but one of the specific tasks of care. The instrumental activities of daily living accounted for most of the need in this category compared to the self care needs. The rapid progression of lung cancer compared to colorectal cancer may explain the need for more assistance in this category. The findings in this study are consistent with research identifying that patients with more advanced stages of disease require more assistance with activities of daily living (Houts et al., 1988; Stetz, 1987). The findings of this study indicate that caregivers of patients with late stage lung cancer need to provide more assistance with physical activities in the initial phase of treatment than caregivers of patients with advanced colorectal cancer.

In the category of Activities of Symptom Management Assistance, the caregivers of patients with colorectal cancer reported providing assistance with more specific tasks of care than the caregivers of patients with lung cancer. Caregivers of patients with colorectal cancer reported the greatest need to provide assistance in this category. This finding may be related to the effects of the disease and initial treatment, especially surgery. Patients with advanced colorectal cancer are more likely to have surgery than patients with advanced lung cancer.

The symptoms in this category seem to provide a link to assistance needed in the other two categories of care. Other researchers have identified that the symptoms of nausea and pain were related to needs for assistance with

instrumental activities of daily living and transportation (Given et al., 1993; Mor et al., 1992; Oberst et al., 1989). This finding was supported in this study as well.

Assistance with some of the specific tasks of care in the Activities of Health Care Assistance category may also be influenced by the symptom of pain. The need for assistance with oral medications was frequently reported by both groups of caregivers in the Activities of Health Care Assistance. This link also occurred with the symptom of constipation which was frequently reported by both groups of caregivers in the Activities of Symptom Management Assistance and the need to provide constipation prevention which was frequently reported in the Activities of Health Care Assistance category.

In the category of Activities of Health Care Assistance, the caregivers of patients with colorectal cancer averaged more specific tasks of care for which assistance was required than caregivers of patients with lung cancer. Both groups of caregivers reported the least need to provide assistance in this category. The majority of the assistance provided in this category was with oral medication administration for both the caregivers of patients with lung cancer and colorectal cancer. The need for assistance with this activity is possibly related to managing the pain of advanced disease and the symptoms resulting from the treatment regimen. Caregivers for patients with lung cancer did not identify any other health

care activities requiring frequent assistance. Caregivers of patients with colorectal cancer reported providing assistance with several more health care tasks with more frequency.

The findings of this study indicate that caregivers for both patients with lung and colorectal cancer are not required to provide as much assistance in this category of care as the others. This may be related to the late stage of the disease and a more conservative approach to treatment with less technical care required. However, the findings that patients with colorectal cancer required assistance with not only a greater number of specific tasks of care, but several different tasks of care in this category may be related to the greater survival rate and more aggressive treatment than for the patient with lung cancer. In addition, more patients with colorectal cancer may have had surgery resulting in needing more assistance with Activities of Health Care.

The results of this study indicate that patients with late stage lung and colorectal cancer in the initial phase of the disease and treatment have different categories of need overall. The caregivers of patients with lung cancer reported providing physical activities of the Activities of Daily Living/Instrumental Activities of Daily Living Assistance category most often. Caregivers of patients with colorectal cancer reported the greatest need for assistance with Activities of Symptom Management Assistance. The

Activities of Health Care Assistance were reported by both groups of caregivers as needing to be provided the least, however the patients with colorectal cancer required more assistance with this category than patients with lung cancer.

Discussion of Results with the Conceptual Framework

The results of this study support the conceptual model from Given and Given (1995) of Continuing Cancer Care Demands and Family Caregiver Burden. The site of cancer (Nature of the Cancer) influenced the tasks of care within the three categories of care needed by patients with late stage cancer and provided by caregivers (Demands on Caregiver and Patient). The caregivers of patients with colorectal cancer identified more frequently providing tasks of care within two of the three categories of care. Many of the tasks of care provided by the caregivers of patients with lung cancer and colorectal cancer were similar, however, there were some differences based on site of cancer. Therefore, it may be concluded that site of cancer influenced the number and type of tasks of care required.

Implications for Advanced Practice Nursing in Primary Care

About 1,382,400 patients and families will have to deal with a new diagnosis of cancer this year (American Cancer Society, 1997). There are also over 7.4 million others who are already living with cancer, many who were diagnosed five or more years ago. Families are providing most of the care at home for these patients. Identifying and assisting

caregivers in providing the needs of patients with cancer at home can improve both patient and caregiver outcomes. The advanced practice nurse in the primary care setting can be a valuable resource to the caregiver of a patient with cancer by assisting them in meeting the demands of their particular situation.

A comprehensive assessment of the needs of the patient with cancer and the assistance that the caregiver provides is imperative in the development of an effective plan for home. Advanced practice nurses working with cancer patients and their caregivers are able to thoroughly assess and evaluate the needs of the patient with cancer and the assistance provided by the caregiver. This assessment should be based on the site of cancer, stage of disease, and phase of treatment. This study identified that the site of cancer impacts the type and frequency caregivers are needed to provide assistance with different tasks of care. It is important for the advanced practice nurse to realize that caregivers of patients with advanced cancer in the initial phase of treatment may assist with similar care needs, however, there are also specific needs for assistance based on the site of cancer. The site of cancer provides information about the possible course of the disease and the type of treatment that will occur. The stage of disease at diagnosis provides information about the extent of the disease and other areas of the body that are or may be affected. The phase of the treatment provides information

about treatments that are occurring and side effects the patients may be experiencing. The site of cancer, the stage of disease, and the treatment phase all provide information about the problems the patient may be experiencing with functional ability, symptoms, and health care activities that may require the assistance of a caregiver.

Assessing the caregivers' perception of the cancer patients needs identifies the caregiver's need for information and skill acquisition. Assessing these needs in the categories used for this study provides a comprehensive assessment of the patients needs and caregiver assistance activities required to meet those needs. The Activities of Daily Living/Instrumental Activities of Daily Living Assistance category identifies the functional disabilities of the patient from disease and treatment effecting self-care and instrumental activities of daily living. According to the findings of this study, assessment should include exploring assistance needs of all of the instrumental activities of daily living, especially transportation, housework, and preparing meals. Both the patients with lung and colorectal cancer required considerable assistance with the instrumental activities, therefore, it is very important to adequately assess this category of care with these patients and their caregivers.

The Activities of Symptom Management Assistance provides information about the symptoms and side effects of the disease and treatment that the cancer patient is

experiencing and those that require the assistance of the caregiver. The advanced practice nurse must be cognizant of the most common symptoms and side effects of the cancer patient in general, as well as, those symptoms that are more specific to the patients particular site of cancer.

Symptoms requiring frequent assistance by both groups of patients in this study included pain, poor appetite, and weight loss. The symptoms experienced more specifically by patients with lung cancer possibly requiring caregiver assistance included nausea, dry mouth, trouble sleeping, vomiting, and shortness of breath. The symptoms experienced more specifically by patients with colorectal cancer possibly requiring caregiver assistance included fatigue, diarrhea and coordination problems.

The Activities of Health Care Assistance identify the treatments and procedures to be carried out in the home and those that require the assistance of the caregiver. The health care activity related to the administration of oral medications in the study frequently required caregiver assistance for both group of patients with cancer. Patients with colorectal cancer required assistance more frequently with several different tasks of care in this category. The tasks of care that are important to explore specifically with patients with colorectal cancer are colostomy care, constipation prevention, special intravenous access and skin care. The health care needs specific to patients with lung

cancer included assistance with constipation prevention, skin and wound care.

A comprehensive assessment of the assistance provided by the caregiver for the cancer patient provides valuable information to the advanced practice nurse in determining the information, skills, supports, and resources that the family needs. This, then, determines the plan of care for the patient and caregiver. Caregivers in this study identified needs that could possibly be better managed with information about community resources to assist with instrumental activities, a better understanding of the symptoms of disease and side effects of treatments, or more knowledge through teaching about the health care procedures required to manage the patients care.

The instrumental activities identified in this study requiring assistance by the caregiver in the early phases of the disease are not difficult to provide, but are often time consuming. Especially transportation, can be difficult because it may require several hours during the day for appointments and treatments. The caregiver may have to lose time from work and/or juggle other family or social obligations to accomplish this task. It is important for the advanced practice nurse to work with the caregiver in identifying other family members or friends who can provide assistance. It is also important to assist the caregiver in accessing community services, such as homemakers, meals on wheels, or transportation services that are available. The

advanced practice nurse can also be instrumental within the health care agency to promote change in the number of hours of care that are provided so that office hours are extended into the evenings and on weekends when it may be more convenient for caregivers to assist the patient to appointments.

Information is a very important component needed by the caregivers in providing assistance with the symptoms of the disease. The advanced practice nurse needs to provide information for the caregivers on how to manage their patient's particular symptoms. Many of the symptoms identified in this study are related to the treatment of the cancer. The advanced practice nurse must educate the caregiver about the disease and treatment and expected side effects related to that treatment regimen. This is new information for the caregivers in most cases and the advanced practice nurse needs to develop ways of providing information that the caregiver can remember or refer to when necessary. This can be accomplished with written materials such as books, pamphlets, or instruction sheets. Information can also be provided through formalized groups. One of the most well-known programs, "I Can Cope," teaches patients and caregivers about cancer, its treatment, and ways to manage the disease. However, advanced practice nurses or physicians are still the most likely sources of information for caregivers. Encouraging caregivers to accompany the patients to office visits, involve them in discussions

regarding the assistance they are providing, and encouraging and following up with phone calls are important strategies in supporting the caregiver (Northouse & Peters-Golden, 1993).

Pain management was also a symptom frequently requiring assistance. The holistic approach of the advanced practice nurse can be a valuable resource to the caregiver in determining the physical, emotional, social, and spiritual impact of pain management for the caregiver and patient. Advanced practice nurses need to discuss the impact of the pain experience on both the patients and caregivers. Yeager, Miaskowski, Dibble, and Wallhagen (1995) found that caregivers reported that patients had significantly higher levels of pain and distress than patients reported. The caregivers also reported experiencing greater distress from the patients pain than the patients reported. This indicates that the amount of assistance that the caregiver in this study reported may be out of proportion to the need of the patient. Therefore, it is important for the advanced practice nurse to conduct teaching and counseling session with both patients and caregivers to facilitate more accurate communication and clear up any misconceptions about the pain experience. Teaching the caregiver about how to assess pain utilizing the pain scale is an important strategy to help in decreasing the anxiety produced in assisting the patient with pain. This may help the caregiver by decreasing the assistance provided in managing

the patients pain to a more realistic and necessary level for the patient.

The advanced practice nurse must be knowledgeable about both pharmacological interventions and non-pharmacological interventions that caregivers can provide. It is important to assist caregivers in this area by providing extensive medication teaching about how to administer pain medications to achieve optimal pain control and that sufficient doses can be provided to maintain adequate pain relief (Yeager et al., 1995). This can be accomplished by providing written material on the cause of cancer pain, the differences between tolerance, dependence, and addiction, the risks and benefits of various pharmacologic and non-pharmacologic methods of pain control, and the reason for administering analgesics around-the-clock. The advanced practice nurse must also be open to non-traditional forms of therapy, such as therapeutic touch and relaxation techniques, that patients and caregivers may identify as wanting to try to relieve pain and promote comfort. Patients should also be provided with a written pain management plan and given instructions regarding who to contact when pain control is not being achieved. Suggestions regarding helpful strategies for taking medications on schedule include using a pill box clearly marked with administration times of the pain medications.

The Activities of Health Care Assistance that the caregiver must provide for the patient frequently require

learning new skills. The advanced practice nurse can assist the caregiver in learning these new skills and determine whether some tasks required are beyond the ability of the caregiver. The advanced practice nurse can access skilled home care services for homebound patients for a short period to teach and supervise new skill acquisition and to further assess and assist in providing supportive services that may be necessary for the patient and caregiver. The advanced practice nurse must provide comprehensive information to the home care agency about the care requirements of the patient and the caregivers ability to provide the care. Areas of support for the family and further teaching needed must also be identified by the advanced practice nurse for the home care agency. The advanced practice nurse must also assist the caregiver and patient in feeling comfortable having a health care provider come into their home by providing information about the home care agency and the type of care they can expect. The caregiver and patient must also be reassured of the advanced practice nurses continued assessment and intervention along with the home care agency.

Oral medication administration was identified most frequently by both groups of caregivers as requiring assistance. It is important to assess all of the different medications that the patient is taking to determine schedule, potential interactions and side effects. Through this assessment some medications may be eliminated or changes may be made related to fewer administrations, side

effects and interactions with other medications being taken. Teaching the caregiver and patient about the intended effects of the medication and potential side effects will assist the advanced practice nurse in evaluating the effectiveness, ineffectiveness or harm to the patient. As with pain management, it is very important for the advanced practice nurse to work with the caregiver and patient in developing a schedule for administering medications that can be followed and is as convenient as possible.

Colostomy care was identified as requiring assistance by the caregivers of patients with colorectal cancer. Oberst and Scott (1988) found that physical self-care requirements were significantly more problematic for ostomy patients than non-ostomy patients up to 60 days after discharge from the hospital. Many of the spouses experienced severe distress 60 days after the patient returned home. The advanced practice nurse can assist patients and caregivers by providing further teaching and support. It may be necessary to refer and collaborate with an enterostomal specialist in assisting to meet the patients and caregivers needs. Arranging for a home care nurse to follow-up with assessment and teaching of the care of the colostomy at home may be very beneficial to the patient and caregiver. Caregivers may also require supportive intervention to manage the emotional distress related to caring for a patient with a colostomy.

The advanced practice nurse must continually reassess and evaluate the assistance being provided by the caregiver as treatment regimens change or are discontinued and as the disease progresses. The rapid decline of some patients diagnosed with late stage disease may necessitate the termination of treatment or the patient may decide to discontinue treatment. The assistance activities of the caregiver may change as the disease progresses to providing more self-care activities of daily living instead of instrumental activities of daily living as the patient becomes more physically debilitated. The symptoms may change from those related to the side effects of treatment, such as, nausea and vomiting to the effects of the disease progression, such as, fatigue, dry mouth, and difficulty breathing. The focus of the health care activities may become more related to loss of body function, such as, providing mouth care and dealing with stool and urinary incontinence.

The advanced practice nurse needs to support the patients decision to discontinue treatment and provide emotional support for the caregiver. Teaching must be continued based on the patients and caregivers changing needs. In the terminal phase of the disease the patient becomes more dependent requiring more assistance from the caregiver with personal activities of daily living. The caregivers need anticipatory guidance regarding the changes that can occur in the patients functional status and how

their role will change and other tasks of care that may be required of them. The advanced practice nurse can assist the caregiver by giving permission to relinquish some of the care, assisting the caregiver to identify other family members or friends who can assist, or by utilizing outside resources to assist in providing respite for the caregiver, such as hospice.

The advanced practice nurse can also assist the patient and caregiver by coordinating the care. This can be accomplished by working with the caregiver and patient to determine the best schedule of activities based on the needs of the patient and the assistance the caregiver provides. Assisting the patient and caregiver to schedule treatments and follow-up appointments at times that are the best for the patient related to their time of optimal physical function and when symptoms are best controlled is important. Home care services can be coordinated to occur between treatment times. Assisting the caregiver to identify other caregivers and how they can best be utilized to provide respite is also very important. The advanced practice nurse needs to follow-up on other services being utilized, such as home care, to evaluate effectiveness and oversee the plan of treatment.

The advanced practice nurse should also encourage the patient and caregiver to express their emotional concerns regarding the diagnosis of cancer and the effects of the disease. The patient should be encouraged to express the

difficulties related to an alteration in physical function, contending with disturbing symptoms, and the need to depend on others for assistance. The caregiver should also be encouraged to express the emotional strain of providing care for someone with cancer and the frustration of trying to assist with symptoms and treatments they frequently do not feel qualified to provide. Identifying support groups available or social worker intervention for the caregiver to assist in coping may be very beneficial.

It is vital to know the type of care the caregiver must provide to assist the patient with cancer based on the site of the cancer, stage of disease, and phase of treatment. A thorough evaluation of activities of daily living, instrumental activities of daily living, symptoms, and health care treatments that the patient needs and the caregiver is providing is important to not only assist the patient, but the caregiver as well. Meeting the needs of the caregiver by developing interventions to assist the caregiver may influence the type of care being provided and the ability of the caregiver to continue to care for the patient for the length of time that is required.

Recommendations for Further Research

The literature review, as delineated previously, revealed that little research has been conducted examining the physical care requirements of patients with lung and colorectal cancer provided by caregivers. Further research is suggested as follows:

(1) Further research is needed to examine the tasks of care provided by caregivers for patients with late stage lung and colorectal cancer over the course of the disease.

This study could be furthered by examining the tasks of care provided by caregivers for patients with late stage lung and colorectal cancer through adjuvant and palliative therapy. This information will be helpful in further identifying the proportion of patients with late stage lung and colorectal cancer needing assistance, the specific tasks of care being provided, and the duration of assistance provided by caregivers throughout the disease trajectory (Given & Given, 1994). It can be anticipated that the level of care and type of care will change across the cancer care trajectory and it would be valuable to have a better understanding of how these needs change for patients with late stage lung and colorectal cancer and how their caregivers adjust to meet them.

(2) Further research is needed to examine tasks of care provided by caregivers for patients with early stage lung and colorectal cancer.

This information would be helpful in further determining the impact stage of cancer has on the type of assistance required compared to this study of caregivers for patients with late stage lung and colorectal cancer. It is anticipated that patients with early stage cancer will have a different course of treatment with a better prognosis. More information about the assistance provided by caregivers

for these patients provides better understanding of the differences in need for caregiver assistance based on stage of cancer.

(3) Further research is needed to examine the tasks of care provided by caregivers for patients based on the site of cancer.

This information would be helpful in identifying the type and degree of assistance required for other cancer diagnoses. Understanding the different specific tasks of care and the category of care provided most frequently by caregivers for different sites of cancer assists health care providers to tailor health care plans to specifically meet the needs of the patient and caregiver.

(4) Further research is needed to examine tasks of care provided by caregivers for cancer patients based on the different treatment regimens patients with cancer experience.

This would provide information about the impact treatment regimens have on the patients functional status, symptoms, and health care interventions needing assistance and the type of assistance required. This would assist health care providers in anticipating when patients are likely to need assistance and what type of assistance is required related to specific treatment modalities.

(5) Further research is needed to identify and test interventions aimed at assisting caregivers or patients with tasks of care.

These studies would identify interventions that are effective in meeting the needs of patients with cancer and their caregivers. Based on this study several of the same specific tasks of care were identified as needing assistance for patients with lung and colorectal cancer indicating that several sites of cancer could be pooled in developing plans of care for these specific tasks of care. The effectiveness of the interventions would be measured by their impact on the quality of care and expected outcomes for the patient and caregiver.

Knowledge about the type of care caregivers are frequently providing is important in determining interventions needed to support these caregivers. Meeting the needs of the caregiver of a patient with cancer may result in improved care provided by the caregiver and better outcomes for the patient. Advanced practice nurses must understand the relationship between the site of cancer, stage of disease, phase of treatment, the treatment regimen, and the assistance required of the caregiver for the patient with cancer. This information will enable advanced practice nurses to more effectively improve the quality of care provided by caregivers to patients with cancer and should improve the quality of life of the caregiver by reducing the quantity, duration, and stress of providing that care.

Summary

This study identified and described the tasks of care, within three broad categories of care, needed by late stage

lung and colorectal cancer patients according to their caregivers. This study also compared the differences in the needs for assistance of patients with lung and colorectal cancer. The findings of the study indicated that the caregivers of patients with lung cancer most frequently assisted with Activities of Daily Living/Instrumental Activities of Daily Living Assistance, followed by Activities of Symptom Management Assistance, and least frequently assisted with Activities of Health Care Assistance. Caregivers of patients with colorectal cancer most frequently assisted with Activities of Symptom Management Assistance, followed by Activities of Daily Living/Instrumental Activities of Daily Living Assistance, and least frequently assisted with Activities of Health Care Assistance.

The caregivers of patients with lung cancer identified providing assistance with more specific tasks of care in the Activities of Daily Living Assistance than the caregivers of patients with colorectal cancer. The caregivers of patients with colorectal cancer identified providing assistance with more specific tasks of care in the Activities of Symptom Management Assistance and Activities of Health Care Assistance than the caregivers of patients with colorectal cancer.

The specific tasks of care identified by caregivers as most frequently needing to be provided in the three categories of care were very similar for both groups of

caregivers. The caregivers identified assisting with transportation, housework, preparing meals, and shopping in the Activities of Daily Living/Instrumental Activities of Daily Living Assistance category. In the Symptom Management Assistance category, poor appetite, pain and weight loss were most frequently identified by the caregivers and in the Activities of Health Care Assistance category, administration of oral medications was most frequently identified by both groups of caregivers. However, in this category many of the caregivers of the patients with colorectal cancer reported assisting with colostomy care and constipation prevention, as well.

The expansion of cancer care from acute care settings and into the home where daily management of care is provided primarily by the family will continue as the health care community struggles with ways to decrease the cost of health care in this country. The current fee-for-service system does not provide coverage for many of the services required to effectively manage the cancer patient at home. Home health aides and homemaker services are not covered by most insurances unless the patient requires skilled care. As this study indicates, much of the care required by patients with cancer is not skilled, however, if family members are not able to provide this care the patient may require institutionalization or deteriorate requiring hospitalization. As capitated systems become more prevalent these services may be a cost-effective approach to

maintaining patients at home instead of requiring costly institutionalization or hospitalizations.

Health care professionals in the community need to focus on providing comprehensive assessment, planning, and management of the patient with cancer and their caregivers in the home. Advanced practice nurses, with their holistic approach to health care treatment and management, may be one of the best candidates to fill this need. Advanced practice nurses, as educators, collaborators, and advocates, must seize the opportunity to respond to the needs of patients with cancer and their family caregivers. The patient with cancer, the caregiver, and the advanced practice nurse in collaboration can develop and implement a plan of care that will guide and support the caregiver in providing the assistance that the patient with cancer needs.

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APPENDIX A

SOCIODEMOGRAPHIC INFORMATION

In this first set of questions I'd like to ask for some background information about you and your spouse/relative/friend with cancer.

- 1) Sex of caregiver: (check one) (Interviewer: Code sex of caregiver.)
 ___ Male (1)
 ___ Female (2)
- 2) What is your birth date? (write in)
 ____/____/____
 Month/Day/Year
- 3) What is your relationship to your patient who has cancer? You are his/her ...
 (check one)
- ___ Spouse (1)
 - ___ Parent (2)
 - ___ Daughter/Son (3)
 - ___ Daughter-in-law/Son-in-law (4)
 - ___ Sister/Brother (5)
 - ___ Sister-in-law/Brother-in-law (6)
 - ___ Granddaughter/Grandson (7)
 - ___ Niece/Nephew (8)
 - ___ Aunt/Uncle (9)
 - ___ Other relative (10) (Please specify _____)
 - ___ Friend or companion with whom he/she lives (11)
 - ___ Other non-relative (12) (Please specify _____)
 - ___ NA/Refused (99)

[Interviewer: Once you have established the caregiver's relationship with the patient, then use that term (e.g., spouse, father, mother, etc.) to refer to the patient in the stem of all subsequent questions.]

4. What is your highest level of education completed? (check one)
- ___ No formal education (1)
 - ___ Completed grade school (2)
 - ___ Completed some high school (3)
 - ___ Completed high school (4)
 - ___ Completed some college or technical training (5)
 - ___ Completed college (6)
 - ___ Completed graduate/professional degree (post baccalaureate degree) (7)
 - ___ NA/Refused (9)

(GO TO NEXT PAGE)

NINR/NCI WAVE I CAREGIVER W/O PATIENT TELEPHONE

ID _____/INT _____
DATE ____/____/____

The next set of questions addresses the **present** level of performance of your _____.
I will state an activity and then read the definition before I ask you questions regarding the activity.

(Interviewer: Category definitions are meant for purposes of clarification.)

- 1) **DRESSING:** This category includes the entire process of dressing or being clothed, including change from bed clothing into the set of clothing worn during the day, and change to bed clothing at night. This category DOES NOT include management of clothing during toileting. If your _____ wears bed clothing during the day, answer "NEVER DRESSES." Select the category that best describes your _____'s level of functioning for DRESSING.

- 1a. Three months ago, with regard to dressing, would you say that your _____ ...
(check one)

- ___ **WAS INDEPENDENT** - (did not need help of another person in any part of this activity) (1)
- ___ **NEEDED SUPERVISION ONLY** - (required another person present during activity to watch the patient in case of problems - did not regularly assist) (2)
- ___ **NEEDED SOME PHYSICAL HELP** - (required physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATED (3)
- ___ **NEEDED TOTAL PHYSICAL HELP** - (needed another person to carry out this activity) CARE RECIPIENT DID NOT PARTICIPATE (4)
- ___ **NEVER DRESSED** (5)
- ___ **NA/REFUSED** (9)

- 1b. Currently, with regard to dressing, would you say that your _____ ... (check one)

- ___ **IS INDEPENDENT** (Go to question 2) (1)
- ___ **NEEDS SUPERVISION ONLY** (Go to 1c) (2)
- ___ **NEEDS SOME PHYSICAL HELP** (Go to 1c) (3)
- ___ **NEEDS TOTAL PHYSICAL HELP** (Go to 1c) (4)
- ___ **IS NEVER DRESSED** (Go to 2) (5)
- ___ **NA/REFUSED** (9)

- 1c. Is the reason for this help related to your _____'s ... (check one)

- ___ **Cancer or cancer treatment** (Go to 1d) (1)
- ___ **Other health problem(s)** (Go to 1d) (2)
- ___ **NA/Refused** (9)

(GO TO NEXT PAGE)

NINR/NCI WAVE I CAREGIVER W/O PATIENT TELEPHONE

ID _____ /INT _____
DATE _____ / _____

2. **EATING:** This category includes all types of food and liquid taken by mouth. This includes all types of presentation used – tray, finger foods, etc.; you do not need to use utensils. This does not include selection or preparation of food.

- 2a. Three months ago, with regard to eating, would you say that your _____
(check one)

- ___ **WAS INDEPENDENT** – (did not need help of another person in any part of this activity) (1)
- ___ **NEEDED SUPERVISION ONLY** – (required another person present during activity to watch the patient in case of problems – did not regularly assist) (2)
- ___ **NEEDED SOME PHYSICAL HELP** – (required physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATED (3)
- ___ **NEEDED TOTAL PHYSICAL HELP** – (needed another person to carry out this activity) CARE RECIPIENT DID NOT PARTICIPATE (4)
- ___ **NOT APPLICABLE** – (needed tube feedings, IV's ONLY) (5)
- ___ **NA/REFUSED** (9)

- 2b. Currently, with regard to eating, would you say that your _____ ... (check one)

- ___ **IS INDEPENDENT** (Go to question 3) (1)
- ___ **NEEDS SUPERVISION ONLY** (Go to 2c) (2)
- ___ **NEEDS SOME PHYSICAL HELP** (Go to 2c) (3)
- ___ **NEEDS TOTAL PHYSICAL HELP** (Go to 2c) (4)
- ___ **NOT APPLICABLE** (Go to 3) (5)
- ___ **NA/REFUSED** (9)

- 2c. Is the reason for this help related to your _____ 's ... (check one)

- ___ **Cancer or cancer treatment** (Go to 2d) (1)
- ___ **Other health problem(s)** (Go to 2d) (2)
- ___ **NA/Refused** (9)

- 2d. If someone helps your _____ with eating, who helps ... (check all that apply)

- | | |
|---|---|
| ___ you (primary caregiver) (1) (Go to 2e) | ___ unpaid family (5) (Go to 2f) |
| ___ paid family (2) (Go to 2g) | ___ unpaid friends/others (6) (Go to 2f) |
| ___ paid friends/others (3) (Go to 2g) | ___ unpaid professional (7) (Go to 2f) |
| ___ paid professional (4) (Go to 2g) | ___ NA/Refused (9) |

- 2e. If **you** (primary caregiver) help with eating ...

- (1) In the past week, **how** many times did you help with eating? (write in)

_____ Times per week

(GO TO NEXT PAGE)

NINR/NCI WAVE I CAREGIVER W/O PATIENT TELEPHONE

ID _____ /INT _____
DATE _____ / _____

3. **BATHING:** This category includes all activities of bathing, whether tub or shower or bed bath, such as entry into tub or shower, wetting, soaping, rinsing, exiting, drying body. This does not include washing of head, drying hair, nor dressing or undressing. Select the response that best describes your _____'s level of functioning for bathing.

- 3a. Three months ago, with regard to bathing, would you say that your _____ ...
(check one)

- ___ **WAS INDEPENDENT** - (did not need help of another person in any part of this activity) (1)
- ___ **NEEDED SUPERVISION ONLY** - (required another person present during activity to watch the patient in case of problems - did not regularly assist) (2)
- ___ **NEEDED SOME PHYSICAL HELP** - (required physical help and the presence of another during all or part of this activity) **CARE RECIPIENT PARTICIPATED** (3)
- ___ **NEEDED TOTAL PHYSICAL HELP** - (needed another person to carry out this activity) **CARE RECIPIENT DID NOT PARTICIPATE** (4)
- ___ **NA/REFUSED** (9)

- 3b. Currently, with regard to bathing, would you say that your _____ ... (check one)

- ___ **IS INDEPENDENT** (Go to question 4) (1)
- ___ **NEEDS SUPERVISION ONLY** (Go to 3c) (2)
- ___ **NEEDS SOME PHYSICAL HELP** (Go to 3c) (3)
- ___ **NEEDS TOTAL PHYSICAL HELP** (Go to 3c) (4)
- ___ **NA/REFUSED** (9)

- 3c. Is the reason for this help related to your _____'s ... (check one)

- ___ **Cancer or cancer treatment** (Go to 3d) (1)
- ___ **Other health problem(s)** (Go to 3d) (2)
- ___ **NA/Refused** (9)

- 3d. If someone helps your _____ with bathing, who helps ... (check all that apply)

- | | |
|---|---|
| ___ you (primary caregiver) (1) (Go to 3g) | ___ unpaid family (5) (Go to 3f) |
| ___ paid family (2) (Go to 3g) | ___ unpaid friends/others (6) (Go to 3f) |
| ___ paid friends/others (3) (Go to 3g) | ___ unpaid professional (7) (Go to 3f) |
| ___ paid professional (4) (Go to 3g) | ___ NA/Refused (9) |

- 3e. If you (primary caregiver) help with bathing ...

- (1) In the past week, how many times did you help with bathing? (write in)

_____ Times per week

(GO TO NEXT PAGE)

NINR/NCI WAVE I CAREGIVER W/O PATIENT TELEPHONE

ID _____ /INT _____
DATE _____ / _____

4. **WALKING INSIDE THE HOUSE:** This category includes all upright movement on foot inside the house. MUST MOVE AT LEAST FIVE FEET. May use cane, walker, crutches, or handrail. Select the response that best describes your _____'s level of functioning for walking inside the house.

4a. Three months ago, with regard to walking inside the house, would you say that your _____ ... (check one)

- ___ **WAS INDEPENDENT** - (did not need help of another person in any part of this activity) (1)
- ___ **NEEDED SUPERVISION ONLY** - (required another person present during activity to watch the patient in case of problems - did not regularly assist) (2)
- ___ **NEEDED SOME PHYSICAL HELP** - (required physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATED (3)
- ___ **NEEDED TOTAL PHYSICAL HELP** - (needed another person to carry out this activity) CARE RECIPIENT DID NOT PARTICIPATE (4)
- ___ **WAS UNABLE TO WALK** - (would not bear weight) (5)
- ___ **NA/REFUSED** (9)

4b. Currently, with regard to walking inside the house, would you say that your _____ ... (check one)

- ___ **IS INDEPENDENT** (Go to question 5) (1)
- ___ **NEEDS SUPERVISION ONLY** (Go to 4c) (2)
- ___ **NEEDS SOME PHYSICAL HELP** (Go to 4c) (3)
- ___ **NEEDS TOTAL PHYSICAL HELP** (Go to 4c) (4)
- ___ **IS UNABLE TO WALK** (Go to 5) (5)
- ___ **NA/REFUSED** (9)

4c. Is the reason for this help related to your _____'s ... (check one)

- ___ **Cancer or cancer treatment** (Go to 4d) (1)
- ___ **Other health problem(s)** (Go to 4d) (2)
- ___ **NA/Refused** (9)

4d. If someone helps your _____ with walking inside the house, who helps ... (check all that apply)

- | | |
|--|--|
| ___ you (primary caregiver) (1) (Go to 4e) | ___ unpaid family (5) (Go to 4f) |
| ___ paid family (2) (Go to 4g) | ___ unpaid friends/others (6) (Go to 4f) |
| ___ paid friends/others (3) (Go to 4g) | ___ unpaid professional (7) (Go to 4f) |
| ___ paid professional (4) (Go to 4g) | ___ NA/Refused (9) |

4e. If **you** (primary caregiver) help with walking inside the house ...

- (1) In the past week, how many times did you help with walking inside the house?
(write in)
_____ Times per week

NINR/NCI WAVE I CAREGIVER W/O PATIENT TELEPHONE

ID _____ /INT _____
DATE ____/____/____

5. TOILETING: This category includes: getting to and from toilet (or use of toileting equipment such as bedpan), removal and adjustment of clothing, positioning on toilet, cleaning of body parts, and replacement of clothing. Select the response that best describes your _____'s level of functioning for toileting.

- 5a. Three months ago, with regard to toileting, would you say that your _____ ... (check one)

- ___ WAS INDEPENDENT - (did not need help of another person in any part of this activity) (1)
- ___ NEEDED SUPERVISION ONLY - (required another person present during activity to watch the patient in case of problems - did not regularly assist) (2)
- ___ NEEDED SOME PHYSICAL HELP - (required physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATED (3)
- ___ NEEDED TOTAL PHYSICAL HELP - (needed another person to carry out this activity) CARE RECIPIENT DID NOT PARTICIPATE (4)
- ___ NOT APPLICABLE - (had catheter, colostomy) (5)
- ___ NA/REFUSED (9)

- 5b. Currently, with regard to toileting, would you say that your _____ ... (check one)

- ___ IS INDEPENDENT (Go to question 6) (1)
- ___ NEEDS SUPERVISION ONLY (Go to 5c) (2)
- ___ NEEDS SOME PHYSICAL HELP (Go to 5c) (3)
- ___ NEEDS TOTAL PHYSICAL HELP (Go to 5c) (4)
- ___ NOT APPLICABLE (Go to 6) (5)
- ___ NA/REFUSED (9)

- 5c. Is the reason for this help related to your _____'s ... (check one)

- ___ Cancer or cancer treatment (Go to 5d) (1)
- ___ Other health problem(s) (Go to 5d) (2)
- ___ NA/Refused (9)

- 5d. If someone helps your _____ with toileting, who helps ... (check all that apply)

- | | |
|--|--|
| ___ you (primary caregiver) (1) (Go to 5e) | ___ unpaid family (5) (Go to 5f) |
| ___ paid family (2) (Go to 5g) | ___ unpaid friends/others (6) (Go to 5f) |
| ___ paid friends/others (3) (Go to 5g) | ___ unpaid professional (7) (Go to 5f) |
| ___ paid professional (4) (Go to 5g) | ___ NA/Refused (9) |

- 5e. If you (primary caregiver) help with toileting ...

- (1) In the past week, how many times did you help with toileting? (write in)

_____ Times per week

(GO TO NEXT PAGE)

NINR/NCI WAVE I CAREGIVER W/O PATIENT TELEPHONE

ID _____/INT _____
DATE ____/____/____

6. TRANSFERRING IN AND OUT OF BED: This category includes movement to and from bed, to chair or wheelchair. Devices, bars, and other mechanical aids may be used. Select the response that best describes your _____'s level of independence.

6a. Three months ago, with regard to transferring in and out of bed, would you say that your _____ ... (check one)

- ___ WAS INDEPENDENT - (did not need help of another person in any part of this activity) (1)
- ___ NEEDED SUPERVISION ONLY - (required another person present during activity to watch the patient in case of problems - did not regularly assist) (2)
- ___ NEEDED SOME PHYSICAL HELP - (required physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATED (3)
- ___ NEEDED TOTAL PHYSICAL HELP - (needed another person to carry out this activity) CARE RECIPIENT DID NOT PARTICIPATE (4)
- ___ REMAINED BEDFAST (5)
- ___ NA/REFUSED (9)

6b. Currently, with regard to transferring in and out of bed, would you say that your _____ ... (check one)

- ___ IS INDEPENDENT (Go to question 7) (1)
- ___ NEEDS SUPERVISION ONLY (Go to 6c) (2)
- ___ NEEDS SOME PHYSICAL HELP (Go to 6c) (3)
- ___ NEEDS TOTAL PHYSICAL HELP (Go to 6c) (4)
- ___ REMAINS BEDFAST (Go to 7) (5)
- ___ NA/REFUSED (9)

6c. Is the reason for this help related to your _____'s ... (check one)

- ___ Cancer or cancer treatment (Go to 6d) (1)
- ___ Other health problem(s) (Go to 6d) (2)
- ___ NA/Refused (9)

6d. If someone helps your _____ with transferring in and out of bed, who helps ... (check all that apply)

- | | |
|--|--|
| ___ you (primary caregiver) (1) (Go to 6e) | ___ unpaid family (5) (Go to 6f) |
| ___ paid family (2) (Go to 6g) | ___ unpaid friends/others (6) (Go to 6f) |
| ___ paid friends/others (3) (Go to 6g) | ___ unpaid professional (7) (Go to 6f) |
| ___ paid professional (4) (Go to 6g) | ___ NA/Refused (9) |

6e. If you (primary caregiver) help with transferring in and out of bed ...

- (1) In the past week, how many times did you help with transferring in and out of bed? (write in)

_____ Times per week

NINR/NCI WAVE I CAREGIVER W/O PATIENT TELEPHONE

ID _____ /INT _____
DATE _____ / _____

7. TRANSPORTATION

7a. Three months ago, with regard to getting to places outside of walking distance, i.e., going to the doctor's or grocery shopping away from your _____'s neighborhood ... (check one)

- ___ DRIVE HIMSELF/HERSELF - (did not need help of another person) (1)
- ___ NEEDED SUPERVISION - (required supervision and the presence of another during all or part of this activity) (2)
- ___ NEEDED SOME PHYSICAL HELP - (needed another person to help drive occasionally) (3)
- ___ NEEDED TOTAL PHYSICAL HELP - (needed others to drive) (4)
- ___ NOT APPLICABLE - (others have always done this) (9)
- ___ NA/REFUSED (9)

7b. Currently, with regard to getting places outside of walking distance, i.e., going to the doctor's or grocery shopping away from your _____'s neighborhood ... (check one)

- ___ DRIVE HIMSELF/HERSELF (Go to question 8) (1)
- ___ NEEDS SUPERVISION (Go to 7d) (2)
- ___ NEEDS SOME PHYSICAL HELP (Go to 7d) (3)
- ___ NEEDS OTHERS TO DRIVE (Go to 7d) (4)
- ___ NOT APPLICABLE (Go to 8) (5)
- ___ NA/Refused (9)

7c. Is the reason for this help related to your _____'s ... (check one)

- ___ Cancer or cancer treatment (Go to 7d) (1)
- ___ Other health problem(s) (Go to 7d) (2)
- ___ NA/Refused (9)

7d. If someone helps your _____ with transportation, who helps ... (check all that apply)

- | | |
|--|--|
| ___ you (primary caregiver) (1) (Go to 7e) | ___ unpaid family (5) (Go to 7f) |
| ___ paid family (2) (Go to 7g) | ___ unpaid friends/others (6) (Go to 7f) |
| ___ paid friends/others (3) (Go to 7g) | ___ unpaid professional (7) (Go to 7f) |
| ___ paid professional (4) (Go to 7g) | ___ NA/Refused (9) |

7e. If you (primary caregiver) help with transportation ...

(1) In the past week, how many times did you help with transportation? (write in)

_____ Times per week

NINR/NCI WAVE I CAREGIVER W/O PATIENT TELEPHONE

ID ____ /INT ____
DATE ____ / ____ / ____

8. LAUNDRY

8a. Three months ago, with regard to laundry, would you say that your _____ ...
(check one)

- ___ WAS INDEPENDENT - (did not need help of another person in any part of this activity) (1)
- ___ NEEDED SUPERVISION ONLY - (required another person present during activity to watch the patient in case of problems - did not regularly assist) (2)
- ___ NEEDED SOME PHYSICAL HELP - (required physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATED (3)
- ___ NEEDED TOTAL PHYSICAL HELP - (needed another person to carry out this activity) CARE RECIPIENT DID NOT PARTICIPATE (4)
- ___ OTHERS HAVE ALWAYS DONE THIS (5)
- ___ NA/REFUSED (9)

8b. Currently, with regard to laundry, would you say that your _____ ... (check one)

- ___ IS INDEPENDENT (Go to question 9) (1)
- ___ NEEDS SUPERVISION ONLY (Go to 8c) (2)
- ___ NEEDS SOME PHYSICAL HELP (Go to 8c) (3)
- ___ NEEDS TOTAL PHYSICAL HELP (Go to 8c) (4)
- ___ OTHERS HAVE ALWAYS DONE THIS (Go to 8c) (5)
- ___ NA/REFUSED (9)

8c. Is this help related to your _____'s ... (check one)

- ___ Cancer or cancer treatment (Go to 8d) (1)
- ___ Other health problem(s) (Go to 8d) (2)
- ___ Others have always done this (Go to 8d) (3)
- ___ NA/Refused (9)

8d. If someone helps your _____ with laundry, who helps ... (check all that apply)

- | | |
|--|--|
| ___ you (primary caregiver) (1) (Go to 8e) | ___ unpaid family (5) (Go to 8f) |
| ___ paid family (2) (Go to 8g) | ___ unpaid friends/others (6) (Go to 8f) |
| ___ paid friends/others (3) (Go to 8g) | ___ unpaid professional (7) (Go to 8f) |
| ___ paid professional (4) (Go to 8g) | ___ NA/Refused (9) |

8e. If you (primary caregiver) help with laundry ...

(1) In the past week, how many times did you help with laundry? (write in)

_____ Times per week

(GO TO NEXT PAGE)

NINR/NCI WAVE I CAREGIVER W/O PATIENT TELEPHONE

ID _____ /INT _____
DATE ____/____/____

9. SHOPPING: Includes all types of purchases.

9a. Three months ago, with regard to shopping, would you say that your _____ ...
(check one)

- ___ WAS INDEPENDENT - (did not need help of another person in any part of this activity) (1)
- ___ NEEDED SUPERVISION ONLY - (required another person present during activity to watch the patient in case of problems - did not regularly assist) (2)
- ___ NEEDED SOME PHYSICAL HELP - (required physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATED (3)
- ___ NEEDED TOTAL PHYSICAL HELP - (needed another person to carry out this activity) CARE RECIPIENT DID NOT PARTICIPATE (4)
- ___ OTHERS HAVE ALWAYS DONE THIS (5)
- ___ NA/REFUSED (9)

9b. Currently, with regard to shopping, would you say that your _____ ... (check one)

- ___ IS INDEPENDENT (Go to question 10) (1)
- ___ NEEDS SUPERVISION ONLY (Go to 9c) (2)
- ___ NEEDS SOME PHYSICAL HELP (Go to 9c) (3)
- ___ NEEDS TOTAL PHYSICAL HELP (Go to 9c) (4)
- ___ OTHERS HAVE ALWAYS DONE THIS (Go to 9c) (5)
- ___ NA/REFUSED (9)

9c. Is this help related to your _____ 's ... (check one)

- ___ Cancer or cancer treatment (Go to 9d) (1)
- ___ Other health problem(s) (Go to 9d) (2)
- ___ Others have always done this (Go to 9d) (3)
- ___ NA/Refused (9)

9d. If someone helps your _____ with shopping, who helps ... (check all that apply)

- | | |
|--|--|
| ___ you (primary caregiver) (1) (Go to 9e) | ___ unpaid family (5) (Go to 9f) |
| ___ paid family (2) (Go to 9g) | ___ unpaid friends/others (6) (Go to 9f) |
| ___ paid friends/others (3) (Go to 9g) | ___ unpaid professional (7) (Go to 9f) |
| ___ paid professional (4) (Go to 9g) | ___ NA/Refused (9) |

9e. If you (primary caregiver) help with shopping ...

(1) In the past week, how many times did you help with shopping? (write in)

_____ Times per week

(GO TO NEXT PAGE)

NINR/NCI WAVE I CAREGIVER W/O PATIENT TELEPHONE

ID _____ /INT _____
DATE ____/____/____

10. **HOUSEWORK:** This includes picking up, dusting, light cleaning, vacuuming, or doing dishes.

10a. Three months ago, with regard to housework, would you say that your _____ ...
(check one)

- ☐ **WAS INDEPENDENT** - (did not need help of another person in any part of this activity) (1)
- ☐ **NEEDED SUPERVISION ONLY** - (required another person present during activity to watch the patient in case of problems - did not regularly assist) (2)
- ☐ **NEEDED SOME PHYSICAL HELP** - (required physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATED (3)
- ☐ **NEEDED TOTAL PHYSICAL HELP** - (needed another person to carry out this activity) CARE RECIPIENT DID NOT PARTICIPATE (4)
- ☐ **OTHERS HAVE ALWAYS DONE THIS** (5)
- ☐ **NA/REFUSED** (9)

10b. Currently, with regard to housework, would you say that your _____ ...
(check one)

- ☐ **IS INDEPENDENT** (Go to question 11) (1)
- ☐ **NEEDS SUPERVISION ONLY** (Go to 10c) (2)
- ☐ **NEEDS SOME PHYSICAL HELP** (Go to 10c) (3)
- ☐ **NEEDS TOTAL PHYSICAL HELP** (Go to 10c) (4)
- ☐ **OTHERS HAVE ALWAYS DONE THIS** (Go to 10c) (5)
- ☐ **NA/REFUSED** (9)

10c. Is this help related to your _____'s ... (check one)

- ☐ **Cancer or cancer treatment** (Go to 10d) (1)
- ☐ **Other health problem(s)** (Go to 10d) (2)
- ☐ **Others have always done this** (Go to 10d) (3)
- ☐ **NA/Refused** (9)

10d. If someone helps your _____ with housework, who helps ... (check all that apply)

- | | |
|--|--|
| <input type="checkbox"/> you (primary caregiver) (1) (Go to 10e) | <input type="checkbox"/> unpaid family (5) (Go to 10f) |
| <input type="checkbox"/> paid family (2) (Go to 10g) | <input type="checkbox"/> unpaid friends/others (6) (Go to 10f) |
| <input type="checkbox"/> paid friends/others (3) (Go to 10g) | <input type="checkbox"/> unpaid professional (7) (Go to 10f) |
| <input type="checkbox"/> paid professional (4) (Go to 10g) | <input type="checkbox"/> NA/Refused (9) |

10e. If you (primary caregiver) help with housework ...

(1) In the past week, how many times did you help with housework? (write in)

_____ Times per week

(GO TO NEXT PAGE)

NINR/NCI WAVE I CAREGIVER W/O PATIENT TELEPHONE

ID _____/INT _____
DATE ____/____/____

11. COOKING AND PREPARING MEALS

11a. Three months ago, with regard to cooking and preparing meals, would you say that your _____ ... (check one)

- ___ **WAS INDEPENDENT** - (did not need help of another person in any part of this activity) (1)
- ___ **NEEDED SUPERVISION ONLY** - (required another person present during activity to watch the patient in case of problems - did not regularly assist) (2)
- ___ **NEEDED SOME PHYSICAL HELP** - (required physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATED (3)
- ___ **NEEDED TOTAL PHYSICAL HELP** - (needed another person to carry out this activity) CARE RECIPIENT DID NOT PARTICIPATE (4)
- ___ **OTHERS HAVE ALWAYS DONE THIS** (5)
- ___ **NOT APPLICABLE** -- (had tube feedings, IV's ONLY) (6)
- ___ **NA/REFUSED** (9)

11b. Currently, with regard to cooking and preparing meals, would you say that your _____ ... (check one)

- ___ **IS INDEPENDENT** (Go to next section) (1)
- ___ **NEEDS SUPERVISION ONLY** (Go to 11c) (2)
- ___ **NEEDS SOME PHYSICAL HELP** (Go to 11c) (3)
- ___ **NEEDS TOTAL PHYSICAL HELP** (Go to 11c) (4)
- ___ **OTHERS HAVE ALWAYS DONE THIS** (Go to 11c) (5)
- ___ **NOT APPLICABLE** (Go to next section) (6)
- ___ **NA/REFUSED** (9)

11c. Is this help related to your _____'s ... (check one)

- ___ **Cancer or cancer treatment** (Go to 11d) (1)
- ___ **Other health problem(s)** (Go to 11d) (2)
- ___ **Others have always done this** (Go to 11d) (3)
- ___ **NA/Refused** (9)

11d. If someone helps your _____ with cooking and preparing meals, who helps ... (check all that apply)

- | | |
|---|---|
| ___ you (primary caregiver) (1) (Go to 11e) | ___ unpaid family (5) (Go to 11f) |
| ___ paid family (2) (Go to 11g) | ___ unpaid friends/others (6) (Go to 11f) |
| ___ paid friends/others (3) (Go to 11g) | ___ unpaid professional (7) (Go to 11f) |
| ___ paid professional (4) (Go to 11g) | ___ NA/Refused (9) |

(GO TO NEXT PAGE)

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 back rubs, 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 last 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 1 CAREGIVER W/O PATIENT TELEPHONE

ID _____/INT _____
DATE ____/____/____

A. Symptom

B. Complain of in past two weeks?

C. Did you/anyone assist patient?

D. Total number of minutes in last 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)

ACTIVITIES OF HEALTH CARE

The next set of questions includes health care activities or treatments that your _____ with cancer may or may not require. First I will ask if your _____ with cancer requires this treatment or procedure, and then I will have additional questions about how others help.

Interviewer: The following questions have three sections: A, B, & C.
Ask section A — each item for all caregivers.

If answer in section A is NO — go to next item (i.e., next health care activity).
If answer is section A is YES — go to sections B & C.

(MARK THE APPROPRIATE ANSWERS FOR EACH)

A. Does your _____ require any of the following treatments or procedures?	YES	NO	B. If YES, who helps your _____?	C. In the past week how many times and approximately how long in minutes each time did it take to do this task?
	YES = 1 NO = 2		1 = You (primary caregiver) 2 = Paid family 3 = Paid friends/ others 4 = Paid professional 5 = Unpaid family 6 = Unpaid friends/ others 7 = Unpaid professional (circle all that apply)	If primary caregiver: _____ (choice #1B) If paid help: _____ (#2B,3B,4B) If unpaid help: _____ (#5B,6B,7B) _____ times _____ minutes _____ times _____ minutes (write in)
Interviewer: If more than one helper in each category, add all instances of help together.				

	1	2	1	2	3	4	5	6	7	_____ times _____ minutes	_____ times _____ minutes	_____ times _____ minutes
1. Special exercises/phys. therapy.	1	2	1	2	3	4	5	6	7	_____ times _____ minutes	_____ times _____ minutes	_____ times _____ minutes
2. Oral medications.	1	2	1	2	3	4	5	6	7	_____ times _____ minutes	_____ times _____ minutes	_____ times _____ minutes

A. Does your _____
require any of the
following treatments
or procedures?

YES NO
YES = 1
NO = 2

B. If YES, who helps your
_____?

- 1 = You (primary caregiver)
2 = Paid family
3 = Paid friends/
others
4 = Paid professional
5 = Unpaid family
6 = Unpaid friends/
others
7 = Unpaid
professional
(circle all that
apply)

C. In the past week how many times and approximately how long
in minutes each time did it take to do this task?

If primary caregiver: If paid help: If unpaid help:
(choice #1B) (#2B,3B,4B) (#5B,6B,7B)

_____ times _____ minutes _____ times _____ minutes

(write in)

Interviewer: If more than one helper in each category,
add all instances of help together.

	1	2	1	2	3	4	5	6	7	_____ times _____ minutes	_____ times _____ minutes	_____ times _____ minutes
3. Topical patch for pain management.	1	2	1	2	3	4	5	6	7	_____ times _____ minutes	_____ times _____ minutes	_____ times _____ minutes
4. Injections (ex., pain meds/ insulin).	1	2	1	2	3	4	5	6	7	_____ times _____ minutes	_____ times _____ minutes	_____ times _____ minutes
5. Special IV Access care, (Hickman catheter, PICC line chest port, groshong, other).	1	2	1	2	3	4	5	6	7	_____ times _____ minutes	_____ times _____ minutes	_____ times _____ minutes
6. IV medications/fluids.	1	2	1	2	3	4	5	6	7	_____ times _____ minutes	_____ times _____ minutes	_____ times _____ minutes
7. Infusion and pumps (for chemo, narcotics, or TPN).	1	2	1	2	3	4	5	6	7	_____ times _____ minutes	_____ times _____ minutes	_____ times _____ minutes

C. In the past week how many times and approximately how long in minutes each time did it take to do this task?

	If primary caregiver: (choice #1B)	If paid help: (#2B,3B,4B)	If unpaid help: (#5B,6B,7B)
— times — minutes	— times — minutes	— times — minutes	— times — minutes

(write in)

Interviewer: If more than one helper in each category add all instances of help together.

Interviewer: If more than one helper in each category add all instances of help together.

A. Does your _____
require any of the
following treatments
or procedures?

YES = 1
NO = 2

B. If YES, who helps your
_____?

C. In the past week how many times and approximately how long
in minutes each time did it take to do this task?

- 1 = You (primary caregiver)
2 = Paid family
3 = Paid friends/
others
4 = Paid professional
5 = Unpaid family
6 = Unpaid friends/
others
7 = Unpaid
professional

(circle all that
apply)

If primary caregiver: If paid help: If unpaid help:
(choice #1B) (#2B,3B,4B) (#5B,6B,7B)

_ times _ minutes _ times _ minutes _ times _ minutes

(write in)

Interviewer: If more than one helper in each category,
add all instances of help together.

	1	2	1	2	3	4	5	6	7	_ times _ minutes	_ times _ minutes	_ times _ minutes	_ times _ minutes
12. Care of incision/wound or drainage tube including dressings.	1	2	1	2	3	4	5	6	7	_ times _ minutes	_ times _ minutes	_ times _ minutes	_ times _ minutes
13. Assistance because of incontinence of urine.	1	2	1	2	3	4	5	6	7	_ times _ minutes	_ times _ minutes	_ times _ minutes	_ times _ minutes
14. Urinary catheter/catheter care (suprapubic type included).	1	2	1	2	3	4	5	6	7	_ times _ minutes	_ times _ minutes	_ times _ minutes	_ times _ minutes
15. Ostomy care: urinary; nephrostomy, ileal conduit; external urine collection.	1	2	1	2	3	4	5	6	7	_ times _ minutes	_ times _ minutes	_ times _ minutes	_ times _ minutes

A. Does your _____
require any of the
following treatments
or procedures?

YES NO
YES = 1
NO = 2

(circle
one)

B. If YES, who helps your
_____?

1 = You (primary
caregiver)
2 = Paid family
3 = Paid friends/
others
4 = Paid professional
5 = Unpaid family
6 = Unpaid friends/
others
7 = Unpaid
professional

(circle all that
apply)

C. In the past week how many times and approximately how long
in minutes each time did it take to do this task?

If primary caregiver: If paid help: If unpaid help:
(choice #1B) (#2B,3B,4B) (#5B,6B,7B)

____ times ____ minutes ____ times ____ minutes

(write in)

Interviewer: If more than one helper in each category,
add all instances of help together.

	1	2	1	2	3	4	5	6	7	____ times ____ minutes	____ times ____ minutes	____ times ____ minutes
16. Constipation prevention: medications and/or enemas.	1	2	1	2	3	4	5	6	7	____ times ____ minutes	____ times ____ minutes	____ times ____ minutes
17. Assistance because of incontinence of stool.	1	2	1	2	3	4	5	6	7	____ times ____ minutes	____ times ____ minutes	____ times ____ minutes
18. Ostomy/colostomy care: bowel; external stool collection bag.	1	2	1	2	3	4	5	6	7	____ times ____ minutes	____ times ____ minutes	____ times ____ minutes
19. Testing of urine or stool.	1	2	1	2	3	4	5	6	7	____ times ____ minutes	____ times ____ minutes	____ times ____ minutes

(GO TO NEXT SECTION)

APPENDIX B

NINR/NCI WAVE I PATIENT W/O CAREGIVER TELEPHONE

ID _____ /INT _____
DATE ____/____/____

~~Prior to interview~~ Enter date (month, day and year) and interviewer number on each page, if indicated.

SOCIODEMOGRAPHIC INFORMATION FOR CANCER PATIENT

(1) Sex of patient: (check one) _____ Male (1) _____ Female (2)

(2) What is your birthdate? (write in)

____/____/____
Month/Day/Year

(3) What is your highest level of education completed? (check one)

- _____ No formal education (1)
- _____ Completed grade school (2)
- _____ Completed some high school (3)
- _____ Completed high school (4)
- _____ Completed some college or technical training (5)
- _____ Completed college (6)
- _____ Completed graduate/professional degree (post baccalaureate degree) (7)
- _____ NA/Refused (9)

(4) What is your race or ethnic background? (check one)

- _____ Caucasian/White (1)
- _____ African American/Black (2)
- _____ Mexican American/Hispanic/Chicano (3)
- _____ Native American/Alaskan (4)
- _____ Oriental/Asian/Pacific Islander (5)
- _____ Other (6) (specify _____)
- _____ NA/Refused (9)

(5) What is your marital status? (check one)

- _____ Never married (1)
- _____ Married (2)
- _____ Divorced/Separated (3)
- _____ Widowed (4)
- _____ NA/Refused (9)

(GO TO NEXT PAGE)

NINR/NCI WAVE I PATIENT W/O CAREGIVER TELEPHONE

ID _____ /INT _____
DATE _____ / _____

- 10b. From among all the persons you have indicated that may help you, which one person helps the most or is most willing to help should the need arise? (write in)

Name of person and relationship: _____

Note: We will refer to this person as your PRIMARY CAREGIVER.

- 10c. Does your primary caregiver live with you? (check one)

_____ Yes (Go to question 11) (1)
 _____ No (Go to question 10d) (2)
 _____ NA/Refused (9)

10d.

Interviewer: If not spouse, then get mailing address and telephone number of primary caregiver:

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Telephone: (____) _____

Is this person paid by you, or is anyone paid to assist you?

_____ Yes _____ No

If yes, what is the weekly/monthly wage? \$ _____

11. Because of the need for assistance with cancer, did ... (check one)

_____ You move to caregiver's home (Go to question 11a) (1)
 _____ Caregiver move into your home (Go to 11a) (2)
 _____ You move closer to caregiver (Go to 11a) (3)
 _____ Caregiver move closer to you (Go to 11a) (4)
 _____ You move to a facility that provides care (Go to 11a) (5)

Please describe facility: _____

_____ No one move (Go to question 12) (6)
 _____ NA/Refused (9)

- 11a. If movement occurred, what was the month and year of movement? (write in)

_____/_____
 Month/Year _____ NA/Refused (9)

(GO TO NEXT PAGE)

NINR/NCI WAVE I PATIENT W/O CAREGIVER TELEPHONE

ID _____/INT _____
DATE ____/____/____

5. Considering all these sources of income, what was the combined household income of all household members in 1994? (Please indicate gross income, before deducting taxes.) (check one)

Household Income Categories:

<input type="checkbox"/> 0 - 4,999 (1)	<input type="checkbox"/> 35,000 - 39,999 (8)
<input type="checkbox"/> 5,000 - 9,999 (2)	<input type="checkbox"/> 40,000 - 44,999 (9)
<input type="checkbox"/> 10,000 - 14,999 (3)	<input type="checkbox"/> 45,000 - 49,999 (10)
<input type="checkbox"/> 15,000 - 19,999 (4)	<input type="checkbox"/> 50,000 - 59,999 (11)
<input type="checkbox"/> 20,000 - 24,999 (5)	<input type="checkbox"/> 60,000 - 69,999 (12)
<input type="checkbox"/> 25,000 - 29,999 (6)	<input type="checkbox"/> 70,000 - 79,999 (13)
<input type="checkbox"/> 30,000 - 34,999 (7)	<input type="checkbox"/> 80,000 - 89,999 (14)
	<input type="checkbox"/> 90,000 and over (15)

(Go to question 6)

6. In 1994, did you receive ...

- 6a. Food stamps? (check one)

☐ Yes (Go to 6b) (1)
☐ No (Go to 6d) (2)
☐ NA/Refused (9)

- 6b. How much in food stamps per month? (write in)

\$_____ (Go to 6c)

- 6c. For how many months did you receive food stamps? (write in)

_____ Months

- 6d. Winter heat assistance? (check one)

☐ Yes (1)
☐ No (2)
☐ NA/Refused (9)

7. Do you currently have health insurance? (check one)

☐ Yes (Go to 7a) (1)
☐ No (Go to question 17) (2)
☐ NA/Refused (9)

(GO TO NEXT PAGE)

APPENDIX C

MSU FAMILY HOME CARE CANCER STUDY PATIENT CONSENT FORM page 1 of 2

Title of Research Project: *Family Home Care for Cancer -- A Community-Based Model*

We are asking you to participate in a study to learn how cancer impacts the lives of patients and families and the costs of this disease. You will be asked questions about your health, any assistance needed, visits to doctors and treatment centers and expenditures made for care. Over the coming 12 months you will be contacted at approximately 4, 12, 24 and 52 weeks by the Family Home Care Cancer Study staff. Each interview will take 40 minutes, and you will be asked to complete a mailed questionnaire. If you are willing to participate please read and sign the next page which indicates your consent to begin in this study.

1. The study has been described and explained to me and I understand what my participation will involve.
2. I understand my participation in this study is voluntary, will involve no cost to me, and that my decision will in no way affect my current or future health care, nor involve any additional costs to my health care insurer.
3. I understand that all information will be treated in strict confidence. Information will be presented as a summary of all respondents and not identified with me individually. I understand that within these restrictions, results can, upon request, be made available to me.
4. I understand that no immediate benefits will result from my taking part in this study, but am aware that my responses may add to the understanding of health care professionals and may influence future cancer care.
5. I understand that I have the right to seek further information about this study, and my rights relating to it, by calling 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.
6. I understand that a member of the research staff will review part of my current medical record to obtain a list of my medical diagnoses/problems, and cancer and other treatments. I consent to allow access to this information for information about my home care needs and services and understand that this information will remain strictly confidential.
7. I authorize the Health Care Financing Administration and other health insurers to release information about myself to Barbara A. Given, Professor in the College of Nursing, Michigan State University for the purposes of this research study entitled *Family Home Care for Cancer -- A Community-Based Model* in which I am a participant. The information to be released will include admissions to hospitals, nursing homes, home care agencies, the respective lengths of stay for these admissions, and all health care costs paid by Medicare.
8. I understand that I may withdraw from participation at any time without penalty.

THIS CONSENT FORM
THIS PROJECT EXPIRES:

JUL 05 1990

MSU FAMILY HOME CARE CANCER STUDY PATIENT CONSENT FORM page 2 of 2Title of Research Project: *Family Home Care for Cancer -- A Community-Based Model*

I, _____, state that I understand what is required of me as a participant and agree to take part in this study of family caregivers conducted by the College of Nursing, and the Department of Family Practice in the College of Human Medicine, at Michigan State University.

Patient Signature _____ Date _____

address _____

phone(_____) _____

Witness' Signature _____ Date _____

Investigator's Signature _____ Date _____

UCRHS date _____

Generic 6/30/95

UCRHS APPROVAL FOR
THIS project EXPIRES:

JUN 05 1996

and must be renewed within
11 months to continue.

APPENDIX D

MSU FAMILY HOME CARE CANCER STUDY CAREGIVER CONSENT FORM page 1 of 1Title of Research Project: *Family Home Care for Cancer -- A Community-Based Model*

We are asking you to participate in a study to learn how cancer impacts the lives of patients and families and the costs of this disease. You will be asked questions about your health and expenditures made for care of your friend or family member with cancer. Over the coming 12 months you will be contacted at approximately 4, 12, 24 and 52 weeks by the Family Home Care Cancer Study staff. Each interview will take 40 minutes, and you will be asked to complete a mailed questionnaire. If you are willing to participate please read and sign this page which indicates your consent to begin in this study.

1. The study has been described and explained to me and I understand what my participation will involve.
2. I understand my participation in this study is voluntary, will involve no cost to me, and that my decision will in no way affect my current or future health care, nor the current or future health care of my friend or family member with cancer, nor involve any additional costs to my health care insurer.
3. I understand that all information will be treated in strict confidence. Information will be presented as a summary of all respondents and not identified with me individually. I understand that within these restrictions, results can, upon request, be made available to me.
4. I understand that no immediate benefits will result from my taking part in this study, but am aware that my responses may add to the understanding of health care professionals and may influence future cancer care.
5. I understand that I have the right to seek further information about this study, and my rights relating to it, by calling 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.
6. I understand that I may withdraw from participation at any time without penalty.

I, _____, state that I understand what is required of me as a participant and agree to take part in this study of family caregivers conducted by the College of Nursing, and the Department of Family Practice in the College of Human Medicine, at Michigan State University.

Caregiver's Signature _____ Date _____

Address _____

Name of Patient _____

Witness' Signature _____ Date _____

Investigator's Signature _____ Date _____

UCRHS APPROVAL FOR
THIS project EXPIRES:

UCRHS date _____

Generic 06/30/95

JUN 05 1996

and must be renewed within
11 months to continue.

APPENDIX E

MICHIGAN STATE
UNIVERSITY

June 6, 1995

TO: Barbara A. Given
A230 Life Sciences

RE: IRB#: 92-280
TITLE: FAMILY HOME CARE FOR CANCER--A COMMUNITY-BASED
MODEL
REVISION REQUESTED: 05/25/95
CATEGORY: FULL REVIEW
APPROVAL DATE: 06/05/95

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.

OFFICE OF
RESEARCH
AND
GRADUATE
STUDIES

University Committee on
Research Involving
Human Subjects
(UCRIHS)

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

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

Sincerely,

David E. Wright, Ph.D.
UCRIHS Chair

DEW:kaa/lcp

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APPENDIX F

MICHIGAN STATE
UNIVERSITY.

July 3, 1996

TO: Mary Beth Adyniec
6833 Blythefield Ave. NE
Rockford, MI 49341

RE: IRB#: 96-422
TITLE: THE CAREGIVER'S PERCEPTION OF THE TASKS OF CARE
NEEDED BY THE LATE STAGE LUNG CANCER AND
COLORECTAL CANCER PATIENT
REVISION REQUESTED: N/A
CATEGORY: 1-E
APPROVAL DATE: 07/01/96

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.



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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
David E. Wright, Ph.D.
UCRIHS Chair

DEW:bed

cc: Barbara A. Given

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