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COLORECTAL CANCER: CAREGIVER INVOLVEMENT FROM INITIAL DIAGNOSIS TO THREE MONTHS AFTER DIAGNOSIS

presented by

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COLORECTAL CANCER: CAREGIVER INVOLVEMENT FROM INITIAL DIAGNOSIS TO THREE MONTHS AFTER DIAGNOSIS

By

Rose Ann Birkmeier

A THESIS

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

MASTER OF SCIENCE IN NURSING

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ABSTRACT

COLORECTAL CANCER: CAREGIVER INVOLVEMENT FROM INITIAL DIAGNOSIS TO 3 MONTHS AFTER DIAGNOSIS

By

Rose Ann Birkmeier

Colorectal cancer is one of the three leading cancer sites in people over the age of sixty-five. Many of these elderly will require the assistance of a caregiver at some point after their diagnosis. Despite the prevalence of this disease, little is known about caregiver involvement from diagnosis through the initial treatment phase. This secondary analysis consisted of 48 patients, diagnosed with colorectal cancer and their caregivers. Proposed predictors of increased need for caregiver involvement include: stage, comorbidity, and interval of time in treatment. Outcome variables include specific areas of caregiver involvement.

Factors found to be significant were assistance with ADL's/IADL's and symptom management. Minimal help was needed with health care activities. Knowledge of these factors can help the advanced practice nurse develop appropriate interventions.

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INTRODUCTION

Problem Statement

The National Cancer Institute estimates that approximately 7.4 million Americans alive today have a history of cancer (American Cancer Society (ACS), 1997). Colorectal cancer is the fourth most prevalent carcinoma and the second most frequent cause of death from cancer in the United States (Jessup, Menck, Fremgen, & Winchester, 1997). It is estimated that in the U.S. colorectal cancer will account for 131,200 new cases of cancer in 1997, all of which will require treatment within the health care system (ACS, 1997). Estimations in Michigan alone predict 5,000 new cases of colorectal cancer in 1997. Forty percent of the patients diagnosed with colorectal cancer have distant metastatic disease at the time of presentation (Sigurdson, 1995), and although approximately 80% of patients with colorectal cancer are potentially curable by surgery at presentation, half will die of the disease (Sinicrope & Sugarman, 1995).

Cancer is a disease that presents itself in people of all ages, however colorectal cancer specifically targets the elderly, occurring in men and women in equal numbers (ACS, 1997). Incidence increases steadily after age 40 to the

ninth decade. Colorectal cancer is one of the three leading cancer sites in people over the age of 65 (Engelking, 1997). Many of these elderly patients will require the assistance of a caregiver at some point after their diagnosis. Although research demonstrates the areas of caregiver involvement and the burden of cancer care on family members of elderly patients, this information includes the use of samples that are heterogeneous with respect to type of cancer diagnosis.

Experts predict that by the year 2030, one out of five Americans will be over 65 years of age (U.S. Bureau of the Census, Current Population Reports, 1984). The growing population of the elderly coupled with the fact that colorectal cancer targets the elderly and the mortality risk factors associated with colorectal cancer demonstrates the need to know more about the care of individuals with the disease. 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). The purpose of this study is to identify areas of caregiver involvement for colorectal cancer patients 65 years of age and older and to determine if stage, patient comorbidity and interval of time in treatment have an impact on caregiver involvement.

For many years treatment for patients with cancer involved long and frequent hospitalizations. Currently, new and more efficacious medical interventions have made cancer

a chronic illness, meaning patients' treatments may last for years with only infrequent and brief hospital stays (Siegel, Raveis, Houts, & Mor, 1991). Because of early detection successes and improved therapies, 5-year survival rates in patients with colorectal cancer have increased by 20% overall (Engelking, 1997). The result is the increased need for informal caregiving.

Increasing numbers of elderly in the population, improved and aggressive treatment of chronic illnesses such as cancer, combined with cost saving measures such as shortened length of hospital stays have contributed to the fact that there are now more members of society requiring long-term and chronic supportive care external to the formal health care facilities (Helms, Given, Given, Cheng, Kung, & Stommel, 1997). However, the burden of caring for cancer patients may adversely affect families who lack adequate resources or are insufficiently prepared for it (McCorkle, Yost, Jepson, Malone, Baird, & Lusk, 1993). Additionally, many of these family caregivers are themselves old with chronic health problems.

The family home care of patients with cancer may be accomplished at lower health care costs, but at higher personal costs to family members' emotional, social, physical, and financial well-being. In years past, family caregiving activities were focused on physical tasks, i.e. bathing, dressing and transportation. As cancer care changes from acute episodes of illness involving

hospitalization, to home care of a patient with a chronic illness, caregiver involvement also changes. A better understanding of the tasks of care provided by caregivers is important to help identify the specific skills the patients themselves may need and also to help identify skills needed by the caregiver.

Research in the area of caregiver involvement with colorectal cancer patients is needed to identify situations that may arise as family members assume their new caregiving role. Without this important component, caregivers may become overburdened and they may be unable to continue to provide the care prescribed by the health care team and needed by the patient. Some family caregivers, even though overburdened, will do everything in their power to continue to provide the care but at a compromise to their own health and well-being.

This study specifically addresses "areas of caregiver involvement" for colorectal cancer patients. The areas of caregiver involvement included in this study will be Activities of Daily Living/Instrumental Activities of Daily Living, (ADL's/IADL's) Symptom Management, and Health Care Activities. The study will identify broad areas of caregiving involvement and then go on to identify specific tasks of care within each broad category. The caregiver involvement will be examined at time of initial diagnosis through three months after diagnosis (Wave I -Wave II). This study will then report Wave I and Wave II data. The

impact of comorbidity of the patient, stage of the cancer, and interval of time in treatment on caregiver involvement will also be studied.

Statement of Purpose

Rationale for Study

Advanced practice nurses, in their roles as patient/family educator, advocate, counselor, and clinician, must be aware of what tasks require caregiver assistance and how much time is spent on particular tasks. A concern of the entire health care team should be to identify the tasks of care required with newly diagnosed cancer patients (WAVE I) to those three months (WAVE II) after the initial diagnosis. This information is valuable to the health care team and family members in meeting the needs of the patient and caregiver before the situation arises in the home care setting.

By studying newly diagnosed colorectal cancer patients at initial diagnosis and again at three months after the initial diagnosis this researcher will attempt to identify the effects that stage of disease, patient comorbidity, and interval of time in treatment have on the patients and caregivers. Ideally, data at six months would be optimal, this is a preliminary study with data at initial diagnosis and three months to determine a trend. According to Given, Given, and Stommel (1994), this interval is consistent with the other longitudinal studies and should aid in the interpretation of the findings. For certain periods during treatment, or as the disease progresses, symptoms may worsen and the physical status of the patient may deteriorate to the point where the patient may require assistance from their caregivers with self care activities such as bathing, dressing and eating, and with functioning such as moving about, climbing stairs and transportation (Kurtz, Kurtz, Given, & Given, 1993).

Most of the available literature focuses on planning for the discharge of a patient after an acute episode of illness (Perry & Roades de Meneses, 1991; Harrington, Lackey, & Gates, 1995), or on the care of patients with cancer (both at home and in a hospice) during the terminal phase of the illness (Yost, McCorkle, Buhler-Wilderson, Schultz, & Lusk, 1993; Shonwetter, 1996; Herbst, Lynn, Mermann, & Rhymes, 1995; McMillan, 1996; Greisinger, Lorimor, Aday, Winn, & Baile, 1997). However, in the chronic phase of the illness, patients may be experiencing not only symptoms of the disease itself, but also the sequelae of chemotherapy and radiation therapy, such as nausea and vomiting, anorexia, weight loss, and weakness (Given & Given, 1994; Carey, Oberst, McCubbin, & Hughes, 1991). These factors have direct implications for the level of assistance needed. The physical and psychological complications of the disease and the intense treatment regimens are often severe, protracted sources of stress for patients and their familial caregivers. Home care arrangements can collapse if the informal network becomes

too stressed due to increased caregiver burden resulting from disease progression, treatment intensity, or a depletion in available resources (Mor, Masterson-Allen, Houts & Siegel, 1991).

As cancer care moves into the home, families assume greater responsibility for the completion of courses of therapy, the moderation of the impact of that therapy on the patient, and the outcomes of treatment. The home care needs (tasks of care) of a specific cancer patient depend on the site of cancer, the stage of disease progression, and the phase and aggressiveness of treatments. The complexity of care needs also depends on the patient's age, general health and level of functioning prior to the cancer diagnosis, the site and stage of disease, and the geographic distance between the patient's home and treatment facilities. Patients with comorbid conditions may require extended periods of recovery and may never return to their precancer level of health (Given & Given, 1994).

A thorough understanding of the effects of caring for patients with cancer on family caregivers is required in order to enable nurses to develop effective interventions to support family members in their role of caregiver. Such interventions may in turn have a positive effect on families' abilities to provide care and support for patients with cancer (McCorkle et al., 1993). Specifically, the research questions for this analysis are:

- What are the areas of general caregiver involvement at intake and Wave II? What are the specific tasks of caregiver involvement?
- 2. How do comorbidity, stage and interval of time in treatment of colorectal cancer patients influence specific tasks of caregiver involvement at intake and Wave II?

The actual need versus care provided is by means of caregiver self report. It is the caregivers' perception of patient independence, patient requires assistance with an activity and caregiver provides assistance that will be studied. Caregiver involvement of colorectal cancer patients will be the focus of this study. Also under consideration is the impact of stage of the disease, patient comorbidity, and interval of time in treatment as they relate to caregiver involvement. This information can be used by advanced practice nurses and other health professions as they plan interventions to support patients and their family caregivers.

Conceptual Definitions

The following concepts will be studied in relationship to their impact on caregiver involvement of colorectal cancer patients including: stage of cancer, comorbid conditions, and interval of time in treatment. Information on colorectal cancer, general caregiver involvement and specific tasks of caregiver involvement will also be discussed.

Stage of Cancer

Currently, 40% of the patients diagnosed with colorectal cancer have distant metastatic disease (Sigurdson, 1995). It is important to determine the impact of stage of disease on caregiver involvement of colorectal cancer patients. The diagnosis of cancer places the patient within a course of treatment modalities marked by periods of symptom exacerbation and disability, with increasing dependency needs in the advanced stages of the disease (Given & Given, 1994).

A unified 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. These classifications are then categorized into Stage I through Stage IV, with Stage III and stage IV considered late stage disease (Dollinger & Rosenbaum, 1994). The stage of colorectal cancer describes whether the cancer has remained within the bowel or has spread to other sites. As with all cancers, the appropriate therapy can be decided only when the stage of the cancer has been defined. There have been a number of staging systems for colorectal cancer. Dukes classification was the original system. Since 1985, the TNM classification which corresponds directly with the Dukes system has been

used. This allows an improved definition for the number of lymph nodes involved, a factor that can affect the prognosis (Rosenbaum et al., 1994).

Forty percent of the patients diagnosed with colorectal cancer have distant metastatic disease at the time of presentation to the health care provider for diagnosis (Sigurdson, 1995). With the progression of cancer in the advanced stages, worsening symptoms influence the overall health of the patient. Cancer patients in advanced stages experience loss of independence due to organ failure and/or symptoms. The more advanced the disease the poorer the prognosis.

Comorbid Conditions

Comorbidity among elderly patients may mask early symptoms of cancer, compromise treatment, and compound losses in functioning once the diagnosis is made and treatment initiated. (Given & Given, 1995). According to Jessup, McGinnis, Steele, Menck, & Winchester, (1996), the role of comorbid disease as well as the stage at presentation have been suggested as possible reasons for poorer survival in the elderly. The significance of comorbid conditions in relationship to the cancer diagnosis is that other compromised organs and systems and treatment for these may negatively influence the response to cancer treatment modalities. The presence of comorbid conditions, and the medications needed to treat those conditions place the patient at higher risk for complications from cancer

treatments and may be detrimental to the overall quality of life for the individual, which in turn may increase the need for caregiver involvement (Yancik, Havlik, Wesley, Ries, Long, Rossi, & Edwards, 1996).

In the proposed study, comorbidity was measured from information obtained from medical records and interview questions. A concurrent diagnosis of illnesses such as; hypertension, diabetes, prior cancer, chronic lung disease, cardiovascular disease, stroke, psychiatric problems and arthritis was determined from this data source. This is similar to the comorbidity measurements done by Katz, Chang, Sangha, Fossel, and Bates, (1996).

Interval of Time in Treatment

Length of time in treatment may increase the need for caregiver involvement. Due to the systemic nature of symptoms that may result from chemotherapy, this type of treatment may increase the need for caregiver involvement in symptom management. As chemotherapy treatment continues, a patients' immune system may be challenged resulting in potential for increased infections. This may potentially lead to increased areas of caregiver involvement including activities of daily living, instrumental activities of daily living and health care activities. In this proposed study, interval of time in treatment was measured from information obtained from medical records and interview questions.

Colorectal Cancer

Cancer of the large bowel, or colon and rectum is a highly treatable and often curable disease when localized to the bowel (Guillem, Paty, & Cohen, 1997). It is the second most common cause of cancer death in the U.S. Most colorectal cancers develop in the glands of the inner lining or mucosa and are called adenocarcinomas. Colorectal cancer spreads directly from the mucosa or inner lining through the muscle wall of the bowel and into adjacent tissues. The tumor may metastasize through the lymphatic system to nearby lymph nodes, to the liver through the portal vein and, less frequently, by the bloodstream to the bones or lungs (Rosenbaum, Dollinger & Friedman, 1994).

According to the ACS, 1997, surgery is the most common form of therapy for colorectal cancer. Because 70 to 80 percent of rectal cancers present with disease beyond the rectal wall by either direct extension or lymphatic spread, most rectal cancers require radical resection.

The National Cancer Institute, 1997 reports that recurrence following surgery is a major problem and often is the ultimate cause of death. The prognosis of colon cancer is clearly related to the degree of penetration of the tumor through the bowel wall and the presence or absence of nodal involvement. These two characteristics form the basis for all staging systems developed for this disease. Bowel obstruction and bowel perforation are indicators of poor prognosis.

Because colorectal cancer surgery is a local therapy, its oncologic efficacy is based principally on its rate of local control. The pelvis is the most frequent site of tumor recurrence, a major cause of morbidity and death. Pain caused by nerve invasion, perineal breakdown, and obstruction along with bleeding and fistulization often creates an unmanageable problem. In the United States, attempts to reduce local recurrence and improve survival have emphasized postoperative adjuvant chemotherapy and radiation therapy (Guillem et al., 1997). Permanent colostomy (creation of an abdominal opening for elimination of body wastes) is seldom needed for colon cancer and is infrequently required for rectal cancer. Patients with a tumor situated in the lower part of the rectum (i.e., 0-5 cm from the anal verge) usually require an abdominoperineal resection, resulting in a permanent colostomy (Sprangers, Taal, Aaronson, & Velde, 1995).

General Caregiver Involvement

Caregiving of a post-surgical patient requires a rehabilitation period with weakness, pain, wound care, and possible colostomy care in patients with colorectal cancer. Chemotherapy may be given at scheduled intervals at a clinic. This may involve a treatment period followed by a 3-4 week recovery period, followed by subsequent cycles of chemotherapy. Usually, several cycles of chemotherapy over a 6 to 12 month period are given. Some of the side effects of standard chemotherapy for colorectal cancer are nausea

and vomiting, diarrhea, mucositis, neutropenia, alopecia, skin reactions and fatigue (Baiano, 1997). Radiation therapy involves transportation to and from the radiation treatment center on a daily basis, usually for 6-8 weeks. Increased bowel motility, abdominal cramping, nausea and vomiting, fatigue, hepatitis, proctitis, cystitis and fistula formation are considered toxicities of radiation therapy (Strohl, 1997). Potential areas of general caregiver involvement with these patients are all encompassing and include areas of caregiving such as: activities of daily living, instrumental activities of daily living, areas of symptom management assistance, and areas of health care activities assistance.

According to Braithwaite, (1996), caregiver workload is defined as the activities in which carers engage and the responsibilities which they accept in order to promote the physical and mental well-being of the care recipients. Workload includes task-oriented demands such as providing assistance with daily activities, personal care, supervision, decision-making, and social-emotional demands such as acting as a confidant and organizing social activities. Braithwaite's description of caregiver workload includes several areas of caregiver involvement discussed in this study.

Patients' home care needs extend beyond assistance with personal care and include management of symptoms (especially pain), monitoring and use of equipment, medical care tasks

related to surgery, coordination of care, and monitoring and evaluation of key parameters of health status. Family involvement in patient care is an ongoing process negotiated between the patient and caregiver during the illness and course of treatment (Given & Given, 1995).

Specific Tasks of Caregiver Involvement

In situations where patients are unable to meet self care demands, caregivers must assist the patient by providing necessary tasks of care (Given & Given, 1995). In order to meet the needs of patients with cancer, certain areas of physical assistance are required.

In this study, the primary caregiver identifies the tasks of care provided for the patient. The areas of involvement can include a variety of different tasks of care. The 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 Assistance tasks include assisting with activities of daily living (ADL), such as bathing, dressing, and toileting. In this area, caregivers may also assist with instrumental activities of daily living (IADL), such as transportation, cooking and housework (Given & Given, 1991).

In a study by McCorkle et al. (1993), enforced social dependency is defined as needing help from other people in order to perform activities or roles that under ordinary circumstances an adult can do by herself or himself. The Enforced Social Dependency Scale was modified to consist of two components: personal and social competence. Personal competence comprised six activities judged central to performing as a normal adult: eating, dressing, walking, traveling, bathing and toileting. These are similar to the activities of daily living assistance category used in this study. Activities for social competence include three specific roles: spouse, work and recreational roles.

Level of functional dependency was examined with the enforced social dependency scale (ESDS) in a study by Barsevick, Pasacreta, and Orsi (1995). Included were eating, dressing, walking, traveling, bathing, toileting, activities in the home, activities at work, recreational activities and communication. These categories are also similar to the activities of daily living assistance category used in this study.

The Activities of Symptom Management Assistance category of tasks include assisting with activities devoted to relieving symptoms the patient is experiencing related to the disease and/or treatment (Given & Given, 1991). These symptoms include pain, nausea, poor appetite and fatigue. Given and Given, (1994) identify pain control as a complex symptom to manage. Included in pain management is assisting with both pharmacologic and nonpharmacologic approaches to pain control, record keeping, monitoring the patient, assisting with positioning, ambulation, and applying lotions

to relieve the pain are all tasks of care. Other symptoms discussed included nausea, loss of appetite, and fatigue.

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

Researchers have discussed how caregivers manage cancer patient needs in self care activities such as: bathing, dressing, eating and physical functioning (Kurtz et al., 1993; Barsevick et al., 1995; McCorkle et al., 1993; Mor et al., 1991; Braithwaite et al., 1996). Other studies have looked at caregiver involvement due to the sequelae of chemotherapy and radiation therapy such as nausea, vomiting, anorexia, weight loss, pancytopenia and weakness (Given & Given, 1991; Baiano, 1997; Strohl, 1997; Given & Given, 1994).

In summary, concepts useful in determining need for increased caregiver involvement may be stage of cancer, patient comorbid conditions and interval of time in treatment. Attempts to identify specific areas of caregiver involvement for colorectal cancer patients have been limited (Portenoy, Miransky, Thaler, Hornung, Bianchi, Cibas-Kong, Feldhamer, Lewis, Matamoros, Sugar, Olivieri, Kemeny, & Foley, 1991; Pahlman, Bergstrom, & Glimelius, 1994). However, the diagnosis of cancer, regardless of site, places the patient within a course of treatment modalities marked

by periods of symptom exacerbation and disability, with increasing dependency needs in the advanced stages of the disease (Given & Given, 1994). Throughout a patients' treatment, the symptoms experienced may change from the time of diagnosis through the months of chosen therapy and the recovery process (Kurtz, Given, Kurtz, and Given (1994). The focus of this study will be to further investigate the specific tasks of caregiver involvement in ADL's/IADL's, symptom management, and health care activities for colorectal cancer patients and to determine if stage of disease, patient comorbidity, and interval of time in treatment have an impact on caregiver involvement. This line of inquiry should prove to be valuable information to the health care team in planning specifically to meet those needs.

Conceptual Framework

The stage of the cancer, the number of comorbid conditions of the patient, and the interval of time in treatment may have an influence on the caregiver's involvement and the tasks of care provided for colorectal cancer patients. This study was guided conceptually by the Given and Given Caregiver Model, part of the Family Home Care for Cancer--A Community Based Model, supported by grant #1-R01-NR01915 (Given & Given, 1995).

This model identifies several factors influencing caregiver responses to providing care for a family member with cancer (Figure 1). In their Caregiver Model, Given and





Given (1995) identify that the majority of cancer care in the home is provided by spouses and when spouses are not available, by adult children. Caregiving takes place within a historic family context with existing bonds of affection and reciprocity. The background of the family includes quality of the prior family relationships between the caregiver and the patient which exerts a profound influence on the care relationship and may enhance or complicate the caregiving process. Family networks, the family developmental stage, socioeconomic status and living arrangements may enhance or complicate the caregiving process.

The patient characteristics include the characteristics of age, gender, marital status, role obligations and comorbid conditions. The caregiver characteristics include those of age, gender, marital status, role obligations, and resources are all important to consider when determining if the caregiver will be successful in adapting or unable to adapt at all.

Support can be provided by family and by other informal care systems such as friends, co-workers, neighbors, or church members. Formal care systems such as acute care, Visiting Nurse Association, home care, and hospice may be important aspects of the care environment and care processes for the family living with cancer, especially in late stages. These agencies can assist caregivers to carry out their roles.

A portion of the Given and Given (1995) "Caregiver Model" has been used for this study. This study will focus on the factors involving the Nature of the Cancer and the Demands on Caregiver and Patient (Figure 2). The Nature of the Cancer includes the site of cancer, which is colorectal for all patients in this study, and also stage of cancer at diagnosis, and interval of time in treatment. The Demands on Caregiver and Patient from the original model is referred to as Caregiver Assistance Activities within the categories of care provided for patients by their caregivers. The three categories of care include: 1) the ADL's/IADL's Assistance, 2) the Activities of Symptom Management Assistance, and 3) the Medical Care Tasks, reported in this study as Activities of Health Care Assistance. An assumption of this model is that the Caregiver Assistance Activities will be influenced by the stage of the cancer, comorbid conditions of the patient and interval of time in treatment. This study will focus on the factors involving colorectal cancer patients with different stages of the disease, at the time of diagnosis through three months after diagnosis and the caregiver assistance activities including specific tasks of care. Comorbid conditions of the patient and interval of time in treatment will also be considered. Because the focus of this study is on caregiver involvement of colorectal cancer patients only those areas of the conceptual model which pertain to this will be addressed. The portion of the model addressed will help in determining

Figure 2. Model of Care for Colorectal Cancer Patients

19. Lesting of Urine of Stool		
18 Constitution Drevention		
15 Urinary Ostomy Care	15 Croquent I Iringtion	
14. Urinary Catheter/Catheter Care	14. Constipation	
13. Assist with Incontinence of Urine	13. Dry Mouth	
12. Care of Incision/Wound, Drainage Tube	12. Cough	
11. Care of Ulcers/Bedsores	11. Fever	
10. Skin Care	10. Weight loss	11. Cooking and Preparing Meals
9. Mouth Care	9. Poor Appetite	10. Housework
8. Tube Feedings	8. Vomiting	8. Laundry
7. Intusion Pumps	7. Coordination Problems	7. Transportation
6. IV Medications/Fiulds	6. Diarrhea	6. Transferring In and Out of Bed
5. Special IV Access Care	5. Difficulty Breathing / Shortness of Breath	5. Toileting
4. Injections	4. Fatigue	4. Walking Inside the House
3. Lopical Patch for Pain Management	3. Trouble Sleeping	3. Bathing
	2. Pain	2. Eating
	1. Nausea	1. Dressing
Specific Tasks of Care	Specific Tasks of Care	Specific Tasks of Care
) i -	Activities of Daily Living Assistance
3. Activities of Health Care Assistance	2. Activities of Symptom Management Assistance	1. Activities of Daily Living Instrumental
	CATEGORIES OF CAREGIVER INVOLVEMENT	
	Caregiver Assistance Activities	
	•	Interval of Time in Treatment
		Stage 4-Duke's D Late
		Stage 3-Duke's C
		Stage 2-Duke's B
		Stage 1-Duke's A Early
		Stage 0
	Comorbid Conditions	STAGE OF ILLNESS
	Gender	Colorectal Cancer
	Age	SITE OF CANCER
	Patient Characteristics	Nature of Cancer and Care Situation

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areas of caregiver involvement as they pertain specifically to colorectal cancer patients (Figure 2).

Patient characteristics of comorbid conditions may directly influence the areas of caregiver involvement. Comorbid conditions place the patient at higher risk for dependency and may be a direct predictor of need for increased caregiver involvement especially during the first three months after diagnosis. Stage of the disease, as well as interval of time in treatment, will also be important predictors of need for caregiver involvement. The patient with late stage colorectal cancer can anticipate several treatment modalities. The course of colorectal disease may have periods of exacerbation with reduced health and functional ability followed by periods of remission with improved health and functional status. By focusing on colorectal cancer patients, specific tasks of care may be identified related to caregivers of patients with this disease.

Interval of time in treatment has been added to this study to determine a positive relationship between time in treatment and caregiver involvement. It is assumed that the longer the patient is in treatment the greater caregiver involvement.

Outcomes include caregiver report in three categories: (1) Activities of Daily Living (ADL) Assistance and Instrumental Activities of Daily Living (IADL) Assistance with dressing, eating, bathing, walking inside the house,

toileting, transferring in and out of bed, transportation, laundry, housework, and cooking and preparing meals; (2) dependency in Activities of Symptom Management Assistance with nausea, pain, trouble sleeping, fatigue, difficulty breathing/shortness of breath, diarrhea, coordination problems, vomiting, poor appetite, weight loss, fever, cough, dry mouth, constipation and frequent urination; (3) Activities of Health Care Assistance with special exercise/physical therapy, oral medications, topical patch for pain management, injections, special IV access care, IV medications/fluids, infusion pumps, tube feedings, mouth care, skin care, care of ulcers/bedsores, care of incision/wound, drainage tube, assist with incontinence of urine, urinary catheter/catheter care, urinary ostomy care, constipation prevention, incontinence of stool, colostomy care, testing or urine or stool.

As mentioned earlier, the focus of this study will be the stage of the disease, the number of patient comorbid conditions, and interval of time in treatment. These factors are all important in determining the course of the disease and the level of caregiver involvement needed. In their model, Given and Given (1995) suggest these factors have an influence on outcomes. This study will attempt to support the Given and Given Caregiver Model (1995). Specific areas of caregiver involvement will be reported from Wave I and Wave II data. This will enable the advanced practice nurse and other health care members to develop

strategies to assist caregivers of colorectal cancer patients along the continuum. The goal of nursing interventions within this framework is to assist the patient and caregiver to proactively identify the areas of caregiver involvement and achieve optimal outcomes. Identifying and addressing the areas of involvement for family caregivers is critical and is an important way for advanced practice nurses to help the increasing number of family caregivers of patients with colorectal cancer.

Review of Literature

Research addressing areas of caregiving involvement and amount of time spent on caregiving of colorectal cancer patients over the past 5 years has been limited. Although research shows the areas of caregiver involvement and the burden of cancer care on family members of elderly patients, this information is limited by the use of samples that are heterogeneous with respect to type of cancer diagnosis and also stage of the disease. The hereditary, lifestyle, and environmental risk factors associated with developing colorectal cancer are all documented within the literature. The missing piece of information is what occurs after the disease has presented itself. What are the areas of caregiver involvement of elderly colorectal cancer patients?

This study will attempt to identify the needs specifically of colorectal cancer patients. Cancer is a disease that presents itself in people of all ages, however colorectal cancer specifically targets the elderly,

occurring in men and women in equal numbers (ACS, 1997). Colorectal cancer is one of the three leading cancer sites in people over the age of 65 (Engelking, 1997). Experts predict that by the year 2030, one out of five Americans will be over 65 years of age. The growing population of the elderly coupled with the fact that colorectal cancer targets the elderly and the mortality risk factors associated with colorectal cancer demonstrates the need to know more about the care of individuals with the disease. Many colorectal cancer patients present with late stage disease, and are presented with different treatment modalities including surgery and/or chemotherapy and/or radiation therapy. It is important to be able to differentiate caregiver involvement specifically for elderly colorectal cancer patients. 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). This study will attempt to identify caregiver involvement not only in ADL's/IADL/s, but also assistance in symptom management and health care activities. In the following section the literature on the main concepts is reviewed and summarized.

Activities of Daily Living Assistance Tasks of Care

Hileman and Lackey (1990) identified the needs of 15 patients with cancer and their 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, informational, and those related to household duties. The household category included anything relating to managing or running a household and providing patient care.

In a similar study, (Hileman, Lackey, & Hassanein, 1992) identified the daily living needs of 492 home caregivers of cancer patients. The categories of daily living needs in this study were informational, household, patient care, personal, spiritual and psychological. Caregivers' greatest needs were informational and psychological.

Siegel et al. (1991) studied 483 patients with cancer and their informal caregivers. Patients reported on met and unmet needs in personal care activities (bathing and dressing), instrumental activities (heavy and light housekeeping, cooking, shopping), transportation (medical and general), and home health care (health/treatment assistance). Nearly one fifth of all patients (18.9%) experienced an unmet need. Patients with restricted activity and limited finances were more likely to report unmet needs than other patients in the study. Also the probability of a patient having an unmet need were significantly lower when the caregiver was the spouse. Changes in the daily living needs of 629 patients with advanced cancer receiving chemotherapy and/or radiation therapy were investigated by Mor, Masterson-Allen, Houts and Siegel (1992). 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 review of literature identifies caregivers providing household and patient care needs for the patient. The deficits are that most of the literature is over five years old and health care has been changing drastically over that period of time. Although surgical procedures have remained basically the same for colorectal cancer patients, hospital stays are shorter than they were five years ago. Caregiver involvement for colorectal cancer patients may have changed due to the shortened hospital stays. This study will attempt to identify more specifically the tasks of care currently being provided by the caregivers. The Activities of Symptom Management Assistance

This category of tasks of care include assisting with activities devoted to relieving symptoms the patient is experiencing related to the disease and/or treatment such as pain, nausea, poor appetite and fatigue. Many studies do not include the care task demands related to symptom assistance.

Mor, Masterson-Allen, Houts, and Siegel (1992) reported the prevalence of symptoms experienced by 629 patients with advanced cancer receiving either radiation and/or chemotherapy during and three to six months after the completion of outpatient therapy. More than one half of patients (53%) reported pain at the baseline and 34% more of the patients identified new symptom experience of pain at follow-up, complaints of pain increased to a total of 87%. Having pain at the follow-up was related strongly to the likelihood of acquiring a new need in all domains. Similar reports were noted for diarrhea and shortness of breath.

Portenoy et al. (1992), studied the prevalence and characteristics of pain in ambulatory patients with lung or colon cancer undergoing active chemotherapy or radiation therapy. Almost half of the patients stated that pain produced a moderate or greater degree of interference in general activity and work, and more than half reported moderate or greater interference in sleep, mood, and enjoyment of life. A smaller proportion (30.8%) perceived that pain interfered at least moderately with walking and social relations. The differences between patients with different tumor types were not significant.

Ferrell, Taylor, and Grant (1993) noted that caregivers are faced with many decisions and problems related to medications prescribed for managing symptoms, especially pain. Caregivers have to make decisions about which medication to use, also the type, dose and frequency of each

one. Reminding and encouraging patients to take medications and keeping records are also important pain management tasks performed by families.

Dean and Ferrell, (1991) while researching the symptom of fatigue, found that fatigue was one of the chief predictors of quality of life for long-term survivors of cancer. Fatigue can completely alter the normal cycle of sleep, rest, and activity. Sleep schedules become disrupted and usual routines are destroyed as lives are consumed by exhaustion. All physical functions once assumed to be effortless may become energy-depleting endeavors, and routine tasks may become monumental challenges. It is much easier to teach a family member how to perform a physical task, like body mechanics for lifting in and out of bed, than it is to manage the all-encompassing symptom of fatigue. As stated by Given and Given, (1994) many researchers have noted that such symptoms as fatigue are present for long periods, especially following the conclusion of treatment cycles. The distress that these symptoms engender in both the patient and family members should be a major and intense focus in planning for home care.

Kurtz, Given, Kurtz, and Given (1994) studied symptoms of 208 cancer patients 20 years of age and older, diagnosed with a solid tumor or lymphoma and being treated for new or recurrent disease at the time of the study. This population was followed for a year. This study focused on how patient

age and stage of illness influences the frequency and severity of patients' symptoms and dependencies in functioning. The cancer diagnoses consisted of breast (24%), colorectal/gastrointestinal (21%), lung (16%), lymphoma (14%), urinary/reproductive (13%), head and neck (2%), and other (10%). To accomplish comparison of stages, the patients were divided 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. For every group, the most frequently reported symptom was fatigue. The next four most frequently reported symptoms were pain, nausea, poor appetite and constipation in various orders for the three groups. Through this analysis, a correlation was found between a patients' symptoms and the patients' functional status. The results of this study emphasize the importance of managing symptoms experienced during cancer treatment, as symptoms were shown to be a strong predictor of dependencies in ADL's, therefore, an increased need for caregiver involvement.

The review of literature on symptom management, Mor et al. (1992) Portenoy et al. (1992) Kurtz et al. (1994) included colorectal cancer patients along with patients with many other diagnoses in their population. The deficits are that the activities of symptom management were not identified for different diagnoses. However, overall, the literature suggests that symptom management generally

includes management of symptoms such as fatigue and pain. These studies identified fatigue as an all-encompassing The effects of fatigue can completely alter all symptom. dimensions of social well-being for the survivor of cancer. Fatique interferes tremendously with work, personal activities and responsibilities all which may tend to increase caregiver demands (Dean et al., 1991). Pain is also identified as a very complex symptom to manage. The caregiver must not only be concerned with alleviating the pain, they must be able to decide what medication to give, when to give it, remind the patient it is time to take the medication, keep records and know what medications have been taken, deal with nonpharmacologic pain management, know the proper use of heat or cold application and use of diversional activities (Ferrel et al., 1993). Although common, these symptoms are complex and require the intense focus of health care team members in planning for home care of such individuals (Given & Given, 1995; Ferrel et al., 1993; Dean et al., 1991).

Activities of Health Care Assistance Tasks of Care

Studies specifically aimed at identifying care tasks that deal with health care assistance were limited. Oberst, Thomas, Gass, and Ward, (1989) examined caregiving demands and stress appraisals among family members of 47 patients receiving radiotherapy and found that time spent in caregiving was related to length of time on treatment and patient dependency. Caregiver demands included 10

frequently reported caregiving tasks: medical/nursing treatments, personal care, assistance with mobility, emotional support, monitoring and reporting, provision of transportation, managing illness-related finances, additional household tasks, structuring activities, and managing behavior problems. The most demanding caregiving activities included providing transportation, giving emotional support, and doing extra household tasks. Caregivers with poorer health, less education, and those from lower socioeconomic groups appraised their situations as more harmful and threatening. The cancer diagnosis or stage of the illness were not addressed.

Carey, Oberst, McCubbin, and Hughes (1991) explored 49 family caregivers of patients receiving chemotherapy. Caregiving activities included 14 different categories, emotional support, managing illness-related finances, increasing housework, providing transportation, managing mood/behaviors, monitoring/reporting symptoms/progress, running extra errands, planning activities, scheduling, medical/nursing treatments, assisting with communication, assisting with mobility, increasing care for others and providing personal care to the patient. The study showed that as the patient becomes more dependent and caregiving burden increases, the caregiver views the situation as more threatening and less benign.

Research articles have been limited in their discussion of caregiver assistance with specific activities of health

care. Health care assistance is normally defined in a broad term revolving around medical/nursing treatments that include assistance with oral medications, special IV access care, IV medications/fluids, mouth care and skin care (Oberst et al., 1989; Carey et al., 1991). These studies imply that improving methods for clinical assessment of family environment would help the clinician identify areas of caregiver involvement and help the caregiver with anticipatory guidance. This study will attempt to identify specific activities of health care assistance which will enable the health care provider to better prepare and to alleviate the stress involved in the unknown.

Colorectal Cancer Patient Care Needs

Studies specifically examining the care needs of patients with colorectal cancer were limited. The majority of colorectal cancer research examines prevention and does not address patient care needs. Most of the studies involving care needs of patients are heterogeneous, many include colorectal cancer patients in their population. Patients with specific cancer diagnoses may prove to have different care needs requiring the health care team to be aware of these needs when developing plans of care for patients and caregivers.

In an article by Barsevick et al. (1995) research was reported describing the nature and degree of psychological distress persons experience after receiving a diagnosis of colorectal cancer and describing the effect on functional

dependency during the first 3 months of treatment. The sample consisted of 66 persons who completed interviews before surgery and 1 and 3 months after surgery. Depressive symptoms changed substantially over time in relation to the events of diagnosis and treatment. Having an ostomy, additional treatment, and depressive symptoms were predictors of functional dependency after surgery. For functional dependency 3 months after surgery, having an ostomy and having depressive symptoms before the operation contributed significantly to the prediction of functional dependency. Overall, 22% of the variance in functional dependency 3 months after operation was predicted by this combination of factors. For functional dependency 3 months after surgery, having an ostomy was the best predictor of functional dependency, followed by depressive symptoms, having adjuvant treatment accounted for a small increment of explained variance. Together these factors accounted for 30% of the variance in functional dependency. The findings suggest that depressive symptoms, even at low levels, are important to address because they may reduce patients' ability to function in their usual roles and activities for considerable periods after colorectal cancer surgery.

The quality of life in colorectal cancer patients was studied by Sprangers, Taal, Aaronson, and Velde, (1995). The researchers compared general physical functioning and site-specific symptoms between patients requiring a stoma and patients with intact sphincters. Patients with and

without stomas were found to suffer from flatus in varying degrees. Stoma patients without intact sphincters reported more problems with flatulence and urinary function, whereas patients with intact sphincters report constipation. This information will be helpful to the health care team in anticipating the needs of the colorectal cancer patient and their caregiver prior to discharge from the acute care setting.

Eckhardt, Kanzler, and Bernhard, (1994) investigated whether compliance with a post-operative surveillance program in patients with surgically treated colorectal cancer leads to prolongation of life. The clinical courses of 212 patients who had undergone curative resections for colorectal cancer were monitored for at least five years. Tumor recurrences occurred in 10% of compliant and 14% of noncompliant patients. The researchers concluded that postoperative endoscopic surveillance leads to early tumor detection, and is associated with an improvement in survival in patients with colorectal cancer. This would be useful information in developing a care path for colorectal cancer patients and their caregivers. If the caregivers are made aware of the importance of postoperative endoscopic surveillance, the caregiver could encourage the patient to follow-up by scheduling appointments, offering transportation and re-affirmation of the usefulness of the examination. The results of this study are useful in

helping the caregiver with anticipatory guidance as it relates to caregiver involvement.

To investigate the quality of life during chemotherapy in patients with symptomatic advanced colorectal cancer, Glimelius, Hoffman, Graf, Pahlman, and Sjoden, (1994) asked 70 patients to complete a quality of life questionnaire at every fourth treatment cycle. The results were that 59% of the patients reported their tiredness worsened, 51% reported symptoms had worsened and 34% of patients reported an increase in total pain. However, 30% of the total population reported an improvement in their happiness satisfaction. These worsening symptoms are important when counseling advanced stage colorectal cancer patients and their caregivers regarding palliative treatment and reasonable expectations of the treatment regime.

The review of literature has indicated that the majority of colorectal cancer research examines prevention (Sinicrope & Sugarman, 1996; Kim & Mason, 1996) and does not address patient care needs. The literature specific to colorectal cancer patients' care identifies assistance with depression, pain, and fatigue as being major areas of concern (Barsevick et al., 1995; Sprangers et al., 1995; Eckhart et al., 1994; Glimelius et al., 1993). As mentioned earlier, family members dealing on a daily basis with depression, pain and fatigue of their loved ones have a difficult task to accomplish. Education and guidance from health care personnel will be crucial when assisting

caregivers to manage these complex issues in the home setting.

Stage of Illness

The stage of illness also impacts the cancer patients and their caregivers. Research by Houts, Yasko, Harvey, Kahn, Hartz, Hermann, Schelzel and Bartholomew (1988), examined the unmet needs of persons with cancer, focusing on the period of time in terminal care. Of 629 cancer patients, it was estimated that 72% of the sample experienced at least one unmet service need during this The researchers found that needs related to period. activities of daily living were almost three times as frequent in the terminal period as in the period just after diagnosis, estimating that 42% of the sample needed additional help in this area. Physical unmet needs, such as symptom management, were estimated at 22% of the patients in their sample. There were significantly more unmet needs during the terminal period, compared with just after diagnosis, in activities of daily living, obtaining health care, transportation, and problems with medical staff.

Given, Given, Helms, Stommel, and DeVoss (1997) found that caregivers of patients with recurrent disease experienced a marginally significant difference in impact on depression over time. The type of disease (new or recurrent) did not impact caregivers' reactions to the care they were providing for patients. Instead, patients'

symptoms and symptom experience incurred a greater impact on caregiver depression.

In a longitudinal study by Kurtz et al. (1994) patient depression, immobility, and dependencies in ADL's all were correlated significantly with each other, and all increased steadily with patient stage of illness. Their findings also indicated that as the stage of illness progressed, caregivers experienced higher levels of depression, a greater impact on their health and schedule, and increased involvement in assisting their patients with activities of daily living.

Houts et al. (1988), Kurtz et al. (1994), Mor et al. (1992) included stage of the disease as it relates to the magnitude of caregiver tasks. These studies suggest the needs of the patient increase with late stage disease. Overall, late stage disease has a significant impact on caregiver involvement.

Comorbid Conditions

In a convenience sample of 279 patients with cancer, the trajectories of symptoms and loss of physical functioning over time, the relationships of these variables to age and co-morbidity, and differences existing according to cancer site (breast, lung, colorectal, gastrointestinal, urinary/reproductive, lymphoma, and "other"), were investigated by Kurtz et al. (1993). The patients were surveyed twice; at intake (Wave I, n =279) and 6 months later (Wave II, n=160), cause for attrition was not reported. Findings indicated, at Wave I, that age and comorbidity were significantly correlated, and loss of physical functioning was associated primarily with symptoms and, to a lesser degree, with age. Although comorbidity was only modestly correlated with symptoms and loss of function for the total sample, it was highly correlated with both symptoms and loss of physical functioning for the younger patients (those younger than 60 years of age). In comparing patients with breast cancer to their controls, Satariano, Ragheb, and Dupuis, (1989) found that cases with comorbid conditions were less likely to survive three months after diagnosis. This researcher will attempt to show a positive correlation between co-morbidity and increased need for caregiver involvement.

Interval of Time in Treatment

In a study by Given and Given, (1995) it was found that demands for care change over time in response to the stage of the disease and the phase in the treatment plan. Mor et al. (1995) 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. In a study of cancer patients receiving radiation therapy (Oberst et al., 1991) caregivers identified spending most time providing transportation and increased housework.

Throughout a patients' treatment, the symptoms experienced may change from the time of diagnosis through

the months of chosen therapy and the recovery process. During the early phases of treatment the patient may require relatively little assistance beyond emotional support. However, during the periods of aggressive treatment, care demands may become complex (Given & Given, 1994). Summary

Many studies have focused on the emotional aspects of cancer care. The studies that identify the physical requirements of care emphasize the need for assistance with daily activities and symptom management. Few studies have identified specific tasks of care regarding health care treatments. As mentioned earlier, research regarding colorectal cancer and caregiver assistance is limited. Many studies focusing on the stage of the cancer deal with the emotional aspect of care.

The previous research alerts all health care professionals to the need for continual assessment of the patient's cancer experience and the uniqueness of treatment to each individual. This researcher's line of inquiry will identify specific tasks of care required by patients with colorectal cancer. Taking into consideration stage of the disease, patient comorbidity, and interval of time in treatment, the study will go on to identify the specific activities from newly diagnosed patients to those three months after diagnosis in order to better prepare the caregiver for their new role. The reasons for this line of inquiry are three-fold: 1) As mentioned earlier, research

specifically targeting colorectal cancer is limited. This author's research will study specifically caregiver involvement in colorectal cancer patients and the effect of stage of disease, comorbidity of patients, and length of time in treatment; 2) The three month interval is consistent with other longitudinal studies aforementioned and should aid in the interpretation of the findings. The length of time in treatment may show changes in patients' caregiving needs as they proceed through their treatment modalities. For certain periods during treatment, or as the disease progresses, symptoms may worsen and the physical status of the patient may deteriorate to the point where the patient may need assistance with specific activities; 3) Although research has been limited, it suggests that a) difficulties performing ADL's, IADL's, symptom management, and health care activities increase the need for caregiver involvement, and b) caregiver's inability to manage ADL's, IADL's, symptoms, and health care activities increase the possibility of hospital re-admissions and the use of formal health care systems and essentially, health care costs. Identification of caregiver involvement i.e., specific tasks of care, is an essential piece of knowledge that will prove to be beneficial to all members of the health care team when devising a care path for colorectal cancer patients and their family members.

Methods

Research Design

The information obtained for this study is secondary data analysis of an original study which was a longitudinal descriptive-comparative study of patients with cancer and their caregivers gathered in collaboration between Michigan State University (MSU) College of Nursing, College of Human Medicine, Department 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 #R01NR/CA0915 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.

Study Sample

The original study involved a convenience sample of patient/caregiver dyads from 27 community cancer sites in Michigan. The criteria for inclusion into the study were: 1) adult patients 65 years of age and older; 2) no hospitalization in the previous 60 days; 3) a new diagnosis (an incident case) of either breast, colorectal, lung or prostate cancer; 4) a form of initial treatment beyond palliation. Also, each patient was English speaking, had access to a telephone and was asked to identify his/her primary family caregiver.

The sample for this study is a sub-sample of 48 caregivers of patients with colorectal cancer. The

eligibility criteria for entry into this study is as follows: 1) patients 65 years of age or older; 2) a new diagnosis of colorectal cancer at intake; 3) all patients had a surgical procedure for colon cancer; 4) caregivers must have completed Wave II interview in the parent study. The original study's total population of colorectal cancer dyads, who completed Wave II interviews, were included in this study. A nonprobability convenience sample was obtained for the parent study. The staging of the cancer was determined by an audit of the patients' chart at the original screening.

Data Collection Procedures

This researcher will use secondary data analysis to determine: 1) What are the areas of caregiver involvement of colorectal cancer patients at intake and Wave II? What are the specific tasks of care? 2)How do comorbidity, stage of colorectal cancer patients, and interval of time in treatment influence specific areas of caregiver involvement at intake and Wave II?

The parent study utilized a structured interview conducted by trained data collectors. Training followed a procedure developed by the research staff. This included audiotaping actual interviews after consent to record was given by the patient/caregiver, evaluation of all interviews during the first three months, retraining as interviewers began each new observation period and group meetings of all interviewers three times per year during data collection.

The structured interview took place at four different intervals; intake into study, (Wave I), 12 weeks (Wave II), 24 weeks (Wave III) and 52 weeks (Wave IV). Each interview took place over the phone, taking 45-60 minutes to complete. Data was collected from both the patient and the caregiver. Each dyad was then mailed a self-administered booklet to complete and return for further analysis. Beyond the telephone interviews and the self administered booklets, patient medical records were audited for each patient including; surgical, chemotherapy, radiation therapy, or hormonal therapy. This researcher's study used only the portions of the interviews that are specific to this stated line of inquiry, which included interview items containing Likert scale questions addressing activities of daily living/independent activities of daily living, symptom management and health care activities.

Operational Definitions

For the purpose of this study, the definition of key words are as follows:

To assess <u>comorbidity</u>, a list of 9 frequently occurring chronic conditions was presented in the interview including (hypertension, diabetes, emphysema, cardiovascular, psychiatric, arthritis or rheumatism, fractured hip, prior cancer), and patients were asked to identify those conditions that were diagnosed by a health care professional (see Appendix A). Coded as "0" for none, "1-2" if one to two, and "3+" for three or greater.

The time from intake into the study to Wave II will be measured in days. The time in treatment will be measured in days. Patients receiving chemotherapy within two weeks prior to Wave I were coded as "chemo Wave I", patients receiving chemotherapy within two weeks prior to Wave II were coded as "chemo Wave II".

Staging of colorectal cancer includes early stage (stage I and II) and late stage (stage III and IV). This includes any primary tumor (T1-T4), metastasis to any regional lymph nodes, (N1-N3), and the presence or absence of distant metastasis (MO-M1). It also includes the Dukes classification of Duke's A, B, C, or D. Coded as "1" for early (stage I and II and Duke's A and B) and "2" for late (stage III and IV and Duke's C and D).

General Areas of Caregiver Involvement. The original Family Home Care for Cancer study used three scales to collect data from the caregivers regarding the general areas of caregiver involvement provided. These scales were the activities of daily living and instrumental activities of daily living, the activities of symptom management and the activities of health care assistance (see Appendix B). The general areas of caregiver involvement are defined as a group of several similar activities of care provided by caregivers for patients with cancer. The categories of care have been divided into three groups of activities which include: 1) Activities of Daily Living Assistance and Instrumental Activities of Daily Living; 2) Activities of

Symptom Management Assistance; and 3) Activities of Health Care Assistance (Given & Given, 1995).

Measurement and Scoring

The caregivers were asked to respond to whether assistance had been provided for the patient in each of the categories of tasks of care. Specific areas of caregiver involvement within the category 1) Activities of Daily Living Assistance/Instrumental Activities of Daily Living, include 11 tasks: dressing, bathing, eating, walking inside the house, toileting, transferring in/out of bed, transportation, laundry, shopping, housework, and cooking and preparing meals. The categories 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. The Activities of Daily Living category summated scale was on a score of 0-11.

Category (2) Activities of Symptom Management <u>specific</u> <u>areas of caregiver</u> involvement consists of 15 tasks of care which includes: nausea, pain, trouble sleeping, fatigue, difficulty breathing/shortness of breath, diarrhea, coordination problems, vomiting, poor appetite, weight loss, fever, cough, dry mouth, constipation, and frequent urination. The categories were measured by having the

caregiver respond to whether they or anyone else assisted the patient with a response of yes, or 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 include 19 specific areas of caregiver involvement 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 or urine or stool. The categories 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) 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. The Activities of Health Care Assistance category summated scale was on a score of 0-19.

For the purpose of this study the total scores will be used for Wave I and Wave II data. As supported by a review of the literature, the use of ADLs, (alpha .85) IADL's, (alpha .92) and Symptom management (alpha .90) subscales in combination are good indicators of dependency levels, and for this reason will be used within the context of this study as a measure of caregiver involvement in colorectal cancer patients. Health care activities reliability measures are not available. These scores are based merely on a summated scale, the activity is simply observed, either a caregiver helped with an activity or they did not.

The sociodemographic characteristics of the patient include: (1) age coded as "1" for 65-74 years and "2" for 75 or greater. (2) gender coded as "1" for male and "2" for female (3) comorbid conditions, coded as "0" if none, "1" if one and "2+" if two or greater.

The sociodemographic characteristics of the caregiver include: (1) spouse coded as "0" for spouse and "1" as nonspouse; (2) lives with patient or lives apart, coded as "0" for lives with and "1" for lives apart.

Measurement tools used to collect data from the caregivers or someone else in the original Family Home Care for Cancer study included the activities of daily living, instrumental activities of daily living, symptom management, and activities of health care assistance.

Data Analysis

The dependent variable in this study is area of caregiver involvement. The independent variables are comorbid conditions, the stage of the cancer and interval of time in treatment.

To answer Question 1 in the broad classifications of ADL's/IADL's, Symptom Management and Health Care Activities, and also the specific tasks of care within each of these categories, caregivers' answers were taken from the original questionnaire and data was counted including the numbers of general caregiver involvement and also specific tasks of care. Caregiver involvement scores were studied, categories of change empirically based and significant were formed and patterns were identified.

To answer Question 2 in the specific areas of caregiver involvement, more detailed areas of caregiving involvement were studied. The caregiver answers were taken from the original questionnaire and data was counted including the number of specific areas of caregiver involvement. Caregiver involvement scores were studied, categories of change empirically based and significant were formed and patterns were identified. Logistic regression was used to determine the influence of stage of cancer, comorbidity of the patient, and interval of time in treatment as it relates to ADL's/IADL's and health care activities. Analysis of variance was used to study the influence of stage, comorbidity and interval of time in treatment as it relates

to symptom management. It is expected that caregiver involvement will increase from Wave I to Wave II. Only patient/caregiver dyads that completed Wave II were included in this study.

Protection of Human Subjects

Research participants for this secondary analysis were previously recruited and interviewed for the parent study. 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. After deciding to participate in the study, both the patient and the caregiver were asked to sign an Institutional Review Board approved consent form. 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.

There were no identified risks to the patient/caregiver dyads in the original study, which remains true for this secondary analysis. Confidentiality was ensured by the use of participants' name on the pre-enrollment and paradox form only. These forms provide the names and addresses of participants necessary for the trained interviewers to call and arrange appointments to conduct the interviews for data collection. All other documentation utilized for data analysis is restricted to the use of case numbers only, which are assigned to each dyad on their pre-enrollment form. Trained interviewers have access only to the files containing the pre-enrollment form, paradox form and field notes indicating previous interviews that have been completed. For this secondary data analysis, this researcher will not have access to any identifiers.

For the purpose of this secondary data analysis, this researcher has received approval for this study from the University Committee on Research Involving Human Subjects at Michigan State University (see Appendix C).

Research Limitations

The sample size is small for the number of variables being studied. This along with the absence of a random sampling procedure prevents generalizability to other populations. Another limitation of this study is the length of time required for the telephone interview (45-60 minutes) to take place. This in itself could limit the study to the healthiest of all cancer patients to participate in this study. Radiation and/or chemotherapy treatments takes a toll on patients often rendering them too weak or too ill to remain on the telephone for extended periods of time. Requirements for participants to be English speaking and to have access to a phone may omit an entire racial or ethnic group of the population and also may limit the study from having participants of very low socioeconomic backgrounds. The requirement that the patient must identify a primary caregiver may in itself limit the study from patients that have an inconsistent support system.

Another limitation to the study is that all patients in this study had a surgical procedure as initial treatment, however, the type of procedure was not identified. The fact that patient independence, patient need for assistance and caregiver assistance is reported by the caregiver may prove to be a limitation. The patients' perception of independence, need for assistance and report of caregiver assistance may differ from that of the caregiver. The requirement for the patient's caregiver to remain in the study through Wave II is also a limitation on data collection.

RESULTS

Description of the Sample

The sample consisted of 48 patients, with more than half (n=27, 56%) male and more than half the total sample (n=30, 63%) were between the ages of 65-74. Nearly half (n=21, 44%) of the patients were late stage cancer having 1-2 comorbid conditions (n=23, 48%). Nearly half (n=22, 46%) of all patients received chemotherapy treatment, with the same amount receiving treatment by Wave I (n=11, 23%) versus in chemotherapy treatment by Wave II (n=11, 23%) (see Table 1). As mentioned earlier, only those dyads completing Wave II were studied.

The sample consisted of 48 caregivers, with more than half ($\underline{n}=38$, 79%) female and more than half the total caregiver sample, ($\underline{n}=30$, 66%) over the age of 60 (Table 2).

Table 1.

Frequencies and Percents of Sample Patient Sociodemographic Variables N=48

Demographic Variable	Frequency	Percent
	n	<u>8</u> .
Gender		
Female	21	44
Male	27	56
Patient Age		
65-74	30	63
75 +	18	38
Diagnostic Stage		•
Early*	27	56
Late**	21	44
Reported Comorbid Conditi	ons	
- 0	15	31
1-2	23	48
3+	10	21
Interval of time for trea	tment	
Chemo WI	11	23
Chemo WII	11	23
No Chemo	26	54

* Stage 0, I, or II, **Stage III or IV

Table 2.

Frequencies and Percents of Sample Caregiver Sociodemographic Variables N=48

Demographic Variable	Frequency	Percent
	n	*
Gender		
Female	38	·79
Male	10	21
Caregiver Age		
30-39	3	7
40-49	7	15
50-59	6	13
60-69	15	33
70+	15	33
Frequency missing=2		
Caregiver Relation to Patient		
Spouse	33	69
Non-spouse	15	31
Caregiver Lives with Patient		
Yes	33	69
No	15	31

Most of the caregivers (n=33, 69%) were spouses with the majority (n=33, 69%) living with the patient (See Table 2). Answers to Research Ouestions

 What are the areas of caregiver involvement of colorectal cancer patients at intake and Wave II? What are the specific tasks of caregiver involvement?

To answer Question 1, the broad classifications of ADL's/IADL's, Symptom Management and Health Care Activities caregivers answers were taken from the original questionnaire and data was counted including the number of general caregiver involvement, numbers of frequency and percents were obtained. Nearly half (n=22, 48%) of the Wave I patients were independent in all ADL's/IADL's. In Wave II, nearly two thirds (n=26, 59%) of the patients were independent in all ADL's/IADL's. The top six ADL's/IADL's identified in Wave I and Wave II were studied. Reports of actual caregiver assistance in each of the top six ADL's/IADL's were also reviewed (See Table 3).

Caregiver involvement in ADL's/IADL's at Wave I include the top two categories of housework (n=6, 55%) and laundry (n=4, 36%). In Wave II, caregivers were involved with assistance with housework (n=2, 28%) and transportation (n=3, 27%).

Symptom assistance varies little from Wave I to Wave II with the largest amount of assistance reported throughout the study being the management of nausea, poor appetite, diarrhea, fatigue and pain. Caregiver involvement in

Wave I N=48: Report of Care	Frequency giver Ass	<u>and Perce</u> istance	nt of As	ssist with Top	six ADL/IADL's	Need Identified and
	Caregiver Patient In n	report of idependence \$	Caregi patient n I	rer report of : need Dercent	Frequency Missing n	Caregiver report of assistance n percent
Transportation	7 C	47 0	52		ית הי	N N N
Housework	40	52.2	11	24 24	6T	1 V 1 V 1 V
Cookina	29	63.0		22	9 6	2020
Shopping	29	63.0	16	35	i m	2 13
Bathing	41	89.1	4	6	e	2 50
Wave II N=48						
	Caregiver	report of	Caregiv	/er report of	*Frequency	Caregiver report
	Patient Ir	Idependence	patient	: need	Missing	of assistance
	c	đP	с с	percent	ч	n percent
Transportation	32	74.4	11	26	S	3 27
Laundry	26	59.1	ы	11	17	1 20
Housework	29	65.9	7	16	12	2 28
Cooking	32	72.7	4	6	12	o
Shopping	32	72.7	80	18	80	0
Bathing	43	97.7	1	7	4	1 10
*Frequency missin	g includes	the answer o	f "others	have always don	e this". This may a	ccount for the high
values missing in	the areas	of laundry,	housewor)	t, and cooking wh	ere the female may	have always performed
the task for the	male. Does	not suggest	a depende	ance, the patient	has never perform	ed the IADL.

Table 3.

symptom management includes a report of assistance in the top nine symptoms reported as nausea (n=10, 67%), poor appetite (n=7, 58%), diarrhea (n=9, 45%), trouble sleeping (n=5, 31%), pain (n=6, 29%), fatigue (n=7, 25%) dry mouth (n=3, 19%), weight loss (n=1, 9%), and no assistance for those with the symptom of frequent urination (See Table 4).

There were a total of 4 cases with no symptoms reported for column one and two. Symptom assistance reported by caregiver is for those with symptoms so the percents vary. Independent column shows frequency and percent of those patients that require no assistance.

In regard to health care activities, the majority of the patients (85% to 94%) were independent in five of the top six categories through Wave II. Reports of caregiver assistance at Wave I were limited with oral medications and enemas the only areas of caregiver involvement. At Wave II, caregiver involvement was also limited but included assistance with oral medications, skin care and injections (See Table 5).

In response to research question number 1, assistance with ADL's/IADL's and symptom management appear to be the areas of caregiver involvement throughout Wave I and Wave II. The most frequent area of caregiver involvement (specific tasks of care) for Wave I and Wave II data appear to be in assistance with housework, laundry and transportation, and the management of nausea, poor appetite, diarrhea, fatigue and pain.

Frequency and Perce	ent of Sym	ptoms Recognized	and Repor	ts of Caregiver	Assistance	(N=44)
Wave I	Caregiver Patient Ir	report of idependence	Caregiver r Symptoms re	eport of cognized	Caregiver re Symptom assi	port of stance
	c	percent	Ľ	percent	Ľ	percent
Fatigue	16	36	28	64	7	25
Pain	23	52	21	48	Q	29
Diarrhea	24	55	20	45	6	45
Trouble sleep	28	64	16	36	ъ	31
Dry mouth	27	63	16	37	٣	19
Nausea	29	66	15	34	10	67
Poor appetite	32	73	12	27	7	58
Weight loss	33	75	11	25	1	6
Frequent Urine	32	74	11	25	0	0
Frequency missing=1						
	Caregiver	report of	Caregiver r	·	Caregiver re	port of
Wave II N=44	Patient Ir	idependence	Symptoms re	cognized	Symptoms Ass	istance
	Ľ	percent	u	percent	Ľ	percent
Fatigue	15	34	29	66	4	14
Pain	29	66	15	34	7	47
Trouble sleep	29	66	15	34	4	27
Nausea	30	69	14	31	9	43
Diarrhea	31	71	13	29	4	31
Cough	34	77	10	23		10
Poor Appetite	36	82	8	18	S	63
Dry Mouth	34	81	8	19	4	50
Frequent Urine	38	86	9	14	0	0
Frequency missing=2						

Table 4.

ASSIStance						
Wave I (N=48)	Caregivé Patient	er report of Independence	Caregiv Patient	er report of need	Caregiver assistance	report of
	c	percent	r	percent	u	percent
Oral Medication	19	40	29	60	1	e
Oral Rectedence Oral Care	42	88	9	13	0	0
Tniections	44	92	4	80	0	0
skin Care	44	92	4	8	0	0
I.V. Care	44	92	4	8	0	0
Enemas	44	92	4	ω	1	7
	Caregive	er report of	Caregiv	er report of	Caregiver	Report
	Patient	Independence	Patient	Need	of Assista	ince
Wave II N=48	۲	percent	Ľ	percent	Ľ	percent
Oral Medication	21	44	27	56	1	4
Oral Care	42	88	9	13	0	0
Intections	41	85	7	15	-4	14
Skin Care	45	94	m	6	-1	33
I.V. Care	43	06	5	10	0	0
Enemas	41	85	7	15	0	0

Table 5.

2. How do comorbidity, stage and interval of time in treatment influence specific tasks of caregiver involvement at intake and Wave II?

Using a logistic regression model for nominal levels of the dependent variable, specific tasks of caregiver involvement of ADL's/IADL's, by specified factors of stage, comorbidity, and interval of time in treatment, (independent) variables were produced to determine relationships.

The logistic regression uses maximum likelihood estimation for analyzing relationships between multiple independent variables and a dependent variable that is categorical (Polit & Hungler, 1995). Logistic regression transforms the probability of an event occurring into its odds, that is, into the ratio of one events' probability relative to the probability of a second event. The odds ratio (OR) would be close to one (1) if there were no difference between the two groups of situations. The parameter estimates are the log of the odds ratio. The P value is used to assess whether the observed odds ratio are statistically significant ($P \le 0.05$). The null hypothesis tested within this model is that stage of the cancer, patient comorbidity and interval of time in treatment (independent variables) have no influence on caregiver involvement in ADL's/IADL's.

From the regression, stage, (p-value 0.14, OR .29) comorbidity (p-value 0.35, OR .353) and interval of time in

treatment (p-value 0.81, OR 1.24) (See Table 6) are not good predictors of caregiver involvement. This study revealed a large number of patients that were independent in health care activities. Caregivers were not involved enough with health care activities to conduct an analysis on the small population. Reports of caregiver assistance in these categories were minimal (See Table 5). Therefore, we accept the null hypothesis that stage of the disease, patient comorbidity and interval of time in treatment have no influence on caregivers' involvement with ADL's/IADL's and health care activities. It is important to note that gender of the patient is significant and will be addressed in other findings.

Using an ANOVA model, a one-way analysis of variance for interval levels of the dependent variable "caregiver involvement with symptom management" by each of the specified single factor (independent) variables of stage of cancer, patient comorbidity and interval of time in treatment was produced to determine relationships. The ANOVA model was chosen to test the significance of differences between means (Polit & Hungler, 1995), that is, to assess whether the observed differences among the sample means are statistically significant ($P \le 0.05$). The ANOVA decomposes total variability of a set of data into new components: the variability resulting from the independent variable and other variability (individual differences or

Table 6.

Independent		Parameter		
Variable	DF	Estimate	P Value	Odds Ratio
One Comorbidity	1	-1.80	0.1946	.165
2+ Comorbidity	1	-1.04	0.3511	.353
Male/Female*	1	-3.16	0.0012	.043
STAGE-Early/Late	1	-1.25	0.14	.297
Chemo	1	.21	0.81	1.24

Multiple Regression to Determine Influence of Independent Variables on Caregiver Involvement with ADL's/IADL's Analysis of Maximum Likelihood Estimates

* Significant

measurement unreliability for example). The null hypothesis tested within this model is that stage of the cancer, patient comorbidity and interval of time in treatment (independent variables) have no influence on the amount of caregiver involvement in symptom management.

The statistic calculated in an ANOVA model is the F statistic that compares the variation among groups with the variation within groups (Polit & Hungler, 1995). The calculated value of the F statistic appears under the column labeled F value (Table 7) and its P value is under the heading P>F. For example, the value of F for stage is 0.08 with a P value of 0.77 meaning that an F of 0.08 or larger would occur 77% of the time by chance. Because the P value is large, the observed variation in the sample means can be
Table 7.

Independent Variable	DF	SS	Mean Square	F-value	P> F
Stage Early Late	1	.7004	.7004	0.08	0.77
Comorbidity 0 1-2 3+	3	2.6730	.8910	0.11	0.96
Patient Age 65-74 75+	1	1.1516	1.1516	0.14	0.71
Chemo Wave I Wave II	2	.5825	2.9125	0.35	0.71

ANOVA Model of Independent Variables Influencing Caregiver Involvement in Symptom Management

R-Square 0.04

attributed to chance. The value of F for comorbidity is 0.11 with a P value of 0.96 meaning that an F of 0.11 or larger would occur 96% of the time by chance. The value of F for interval of time in treatment (chemo) is 0.35 with a P value of 0.71 meaning that an F of 0.35 or larger would occur 71% of the time by chance. The value of F for age is 0.14 with a P value of 0.71 meaning that an F of 0.14 or larger would occur 71% of the time by chance. The R-square of .04 tells us that 4% of the variance in the dependent variable (caregiver involvement) can be explained by the independent variables. The answer to the question (How do comorbidity, stage and interval of time in treatment influence specific tasks of caregiver involvement at intake and Wave II?) is stage, patient comorbidity and interval of time in treatment did not impact caregiver involvement in ADL's/IADL's, symptom management or health care activities. Therefore, we accept the null hypothesis.

Discussion

Sample

In this study, a total of 48 caregivers interviews were reviewed to determine reports of caregiver assistance with ADL's/IADL's, symptom management and health care activities. Out of 48 caregivers, 21% were male and 79% were female. Sixty-nine percent of caregivers were spouses, living with the patient and 66 % of the caregivers were 60+ years. Literature by Given and Given (1995) support this information with their findings that caregivers for patients are often women over 55 years of age. This also supports literature of the American Cancer Society (1997), referring back to the statement that colorectal cancer affects men and women equally, which then leaves their counterpart spouse in the caregiving role.

Out of 48 patients in the study 56% were men and 44% were women, 63% were between the ages of 65 and 74 years old, 37% were 75 years or over, supporting the literature by the American Cancer Society (1997) that states colorectal cancer affects men and women in equal numbers and targets the elderly.

Caregiver Involvement in ADL's/IADL's

The majority of the caregivers were involved with instrumental activities of daily living. This is supported in the literature by Siegel et al, (1991) where caregiving included assistance with in bathing, dressing, housekeeping, cooking, shopping and transportation. In this study, the entire population of patients had a surgical procedure for the colorectal cancer. Surgery requires a period of rehabilitation with reduced energy and stamina requiring assistance with activities of long duration and high energy levels, such as housework, shopping and cooking.

Assistance in housework (Wave I 55%-Wave II 28%) and laundry (Wave I 36%-Wave II 20%) were reported as the two most frequent tasks of caregiver involvement. Personal care tasks, such as bathing and dressing, were not reported frequently by the caregivers in this study. However, in the early phase of disease, colorectal cancer patients are still functionally able to perform their own personal care, but require assistance with transportation, shopping, and housework mainly due to the post operative state. The demands for care change over time in response to the stage of the disease and phase in the treatment plan (Given & Given, 1995).

The initial phase of treatment frequently includes surgery, followed by radiation and or/chemotherapy.

Radiation treatments or chemotherapy require cancer patients to travel frequently, explaining the need for frequent assistance with transportation. These findings indicate that patients with colorectal cancer depend on their caregivers to provide assistance with instrumental activities of daily living, especially housework, laundry, transportation, shopping and cooking. 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 i.e. surgery and/or chemotherapy. If the disease progresses further, the patient is more likely to require the assistance of the caregiver in personal care activities.

Upon further investigation of caregiver assistance with ADL's/IADL's, it was found that the caregivers were involved in assisting patients with early versus late stage disease almost evenly. Caregivers of patients with late stage disease were not involved in ADL's/IADL's to a greater extent. The amount of caregiver involvement in ADL's/IADL's for patients receiving chemotherapy treatments by Wave I was similar to patients receiving chemotherapy treatments by Wave II. The number of comorbidities of a patient did not prove to show a difference in caregiver involvement in ADL's/IADL's.

Caregiver Involvement in Symptom Management

The top eight categories of caregiver assistance with symptoms reported were nausea, poor appetite, diarrhea,

fatigue, pain, trouble sleeping, dry mouth and weight loss. The entire population had undergone surgery for their cancer which may account for the high incidence of fatigue, pain, diarrhea and trouble sleeping which were symptoms typically found in patients recovering from surgery. Also, by Wave II, 46% of the population were receiving chemotherapy. Twothirds of the caregivers were involved with the management of nausea, while 45% assisted with the management of diarrhea. These findings are supported by research in the field, when patient samples included colorectal patients, examining cancer and it symptoms (Steele, 1995; Kurtz et al., 1993; Kurtz et al., 1994, Mor et al., 1994). Diarrhea has been identified as one of the clinical signs that may alert a clinician to the potential diagnosis of colorectal cancer (Steele, 1995), therefore, due to the diagnosis, this symptom can be expected to be present in a large percent of the population. Within this sample, 45% of the caregivers reported assistance with diarrhea at Wave I with improvements to 31% at Wave II.

Previous literature also supports the findings that fatigue, pain, nausea, poor appetite, and constipation were among the leading symptoms found in patients diagnosed with a solid tumor or lymphoma (Kurtz et al., 1994).

Symptom complaints that may be related to the method of intervention of chemotherapy included nausea, vomiting, altered taste, dizziness and fatigue. Forty-six percent of the patients in this study were receiving chemotherapy by

Wave II. The nature of the treatment causes more systemic symptomatology which may have accounted for the wide variety of symptom complaints. These systemic symptoms may have occurred in addition to, or may lead to other symptoms such as fatigue, nausea, diarrhea, or disturbed sleep.

Also, in this study, fatigue and pain were symptoms requiring caregiver assistance, with fatigue as 25%, Wave I and 14%, Wave II; and pain at 29%, Wave I and 47%, Wave II. Research to support these findings is evident in a study by Given and Given, 1994, that found the distress that fatigue engenders in both the patient and family members should be a major and intense focus in planning for home care. Dean and Ferrell, (1991), found that fatigue was one of the chief predictors of quality of life for long-term survivors of cancer. Ferrell et al. (1993), noted that patients and caregivers are faced with many decisions and problems related to medications prescribed for managing symptoms, especially pain. The findings in this study suggest advanced practice nurses must be able to develop a plan for the patient and careqiver in assisting with the management of these complex symptoms including fatigue and pain. Caregiver Involvement in Assistance with Health Care Activities

In the Activities of Health Care Assistance category, although minimal, caregivers of patients reported assistance with oral medications, injections, skin care, and enemas as the top four categories. In this study, 85% to 94% of the

patients were independent or did not require health care activities through Wave II. 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. As noted above, Ferrel et al. (1993) indicated that patients and caregivers must make many decisions and handle many problems regarding medications.

Although minimal, assistance with oral medications was evident in both Wave I and Wave II. The initial phase of treatment to manage the disease and control the side effects may influence this area of caregiver involvement. In the category assistance with health care activities, the emphasis should be put mainly on helping the caregiver assess the patients' need and determine the type, amount and frequency of oral medications. It would also be important to evaluate if the medication relieved the symptoms, develop a plan and implement it, if a new course of action was needed.

Stage of the Cancer and Caregiver Involvement

The results of this study showed no relationship with the independent variable stage of the cancer and caregiver involvement. However, due to the small sample size, generalizability to other populations is not feasible. Research by Houts et al. (1988) found that caregiver involvement related to activities of daily living were

almost three times as frequent in the terminal period as in the period after diagnosis, estimating that 42% of the sample needed additional help in this area. According to Kurtz et al. (1994), patient depression, immobility, and dependencies in ADL's all were correlated significantly with each other, and all increased steadily with patient stage of illness. Their findings also indicated that as the stage of illness progressed, caregivers experienced higher levels of depression, a greater impact on their health and schedule, and increased involvement in assisting their patients with activities of daily living. It is important to note that, in this study, 44% of the population were experiencing late stage disease and 69% had elderly spouses as their caregivers. 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. Previous research suggests caregivers' involvement will increase over time. Comorbidity of the Patient and Caregiver Involvement

The results of this study showed no relationship with the independent variable patient comorbidity and caregiver involvement. Previous research suggests a correlation, Kurtz et al. (1993) found that age and comorbidity were significantly correlated to symptoms and loss of physical functioning for the younger patients (those younger than 60 years of age). One study reported that women diagnosed with

breast cancer who had 2 or more comorbidities were more likely to die from their breast cancer (Satariano, 1993). Although this study did not focus on people below age 65 and did not involve breast cancer patients, these findings are significant and should be considered in future work to determine the specific relationship or comorbidity and caregiver involvement. Within this study, all the patients are 65 years old or greater and most (n=33, 69%) have one or more comorbidity. Yancik et al. (1996) report higher numbers of comorbid conditions for patients with advancing Thus, the aging of the population further underscores age. not only the urgent need for greater attention to cancer in the elderly, but also the need for expansion of interest in the concomitant comorbidity burden of this age group in determining what is effective therapy for elderly patients. The patients in this study are elderly, many have one or more comorbid conditions, all have had surgery for their cancer and over half are undergoing chemotherapy treatments, factors that should be considered when planning for colorectal cancer patients' home care needs. Previous research suggests that caregiver involvement will increase with cancer patients experiencing pre-existing comorbid conditions (Kurtz et al., 1993).

Interval of Time in Treatment and Caregiver Involvement

The results of this study showed no relationship with the independent variable of interval of time in treatment and caregiver involvement. It should be noted that in

addition to the systemic nature of the symptoms that may result from chemotherapy, this type of treatment can also diminish a patient's immune system. This effect of chemotherapy leaves a patient more susceptible to opportunistic organisms, which may result in the patient experiencing frequent upper respiratory tract infections or influenza. Therefore, symptom complaints such as fever, cough, or difficulty breathing may be a result of the treatment for colorectal cancer as opposed to the cancer itself.

This study was unable to show a relationship with interval of time in treatment and an increase in caregiver involvement. The wide variety of symptom assistance voiced by this sample may be attributed to a patient's chosen method of treatment or may be related to a patients' preexisting medical condition. Research by Sprangers et al. (1995) found that diarrhea, urinary problems (with increased incidence in patients receiving stomas), and disturbed sleep are among the most frequently occurring symptoms in patients undergoing surgery for the treatment of their colorectal cancer. The results of that study are consistent with the findings within this inquiry, showing two of the three symptoms identified (diarrhea and disturbed sleep) were among the top eight of the most frequently occurring problems requiring caregiver involvement. It would only make sense then, that length of time in treatment will have

an impact on caregiver involvement, further research with a larger population is needed to support this statement.

This study focused on the interval of time in treatment by determining if chemotherapy preceded the Wave I and Wave II interviews by two weeks. By Wave I, 23% of the patients were receiving chemotherapy, at Wave II, another 23% were receiving chemotherapy treatments. The results of this study show an increase in caregiver involvement with the symptoms of pain and dry mouth. This holds true in the literature for symptoms experienced due to chemotherapy/radiation treatments (The other six symptoms decrease slightly, suggesting that symptoms experienced at initial diagnosis either stay the same or increase in severity during chemotherapy treatment). According to previous research, caregiver involvement will increase as the length of time in treatment increases. It would be interesting to follow this study through to Wave III to see the impact of chemotherapy six months from diagnosis. Other Findings

The lack of statistical significance may be due to the small sample size. Furthermore, the similarities of the population studied may also have an impact on the statistical significance. All patients were 65 years of age or older. Of the 48 patients in the study, nearly 50% were male versus female, while close to 50% of the patients experienced early versus late stage disease. Nearly seventy percent of the population experienced at least one comorbid

condition with one half receiving chemotherapy treatments by Wave II. The homogeneity of the population could prove to have an impact on the statistical outcome. Therefore, further research is recommended in this area.

The lack of statistical significance of the impact that the independent variables had on the dependent variable brought about further exploration of the data. Of interest were: 1) the unmet need that was apparent in the patients report of symptoms. For the purpose of this research, unmet patient need is being defined as any caregiver identified symptom experienced by the patient that the caregiver does not report as managing. 2) the independent variable of gender proved to be significant in ADL's/IADL's.

1. The caregiver identified area of assistance is evident in ADL's/IADL's and symptom management. ADL's/IADL's (see Table 3) suggests a lack of assistance in all 6 categories through Wave II. Of those caregivers that identified an area of assistance in ADL's/IADL's at Wave I, 9% to 55% of caregivers reported rendering assistance. For Wave II, actual caregiver assistance ranged from none to 29% for those identifying a need in an area of assistance.

The impact of stage of disease, comorbidity of patient, and interval of time in treatment was non-significant in relation to caregiver involvement in symptom management. However, on exploration, it appears that caregiver reports of patient needs are greater than the caregiver involvement

in symptom management. Symptom management (see Table 4) suggests an unmet patient need in all 9 categories in Wave I and Wave II data. Caregiver assistance in Wave I ranged from no help to help for 67% of those that identified a need for assistance in a particular area. Data from Wave II. shows caregiver assistance ranged from no help to 63% of assistance in an identified area. Of particular interest is the unmet need of fatigue management, 64% of caregivers identified a need for assistance in Wave I and 66% identified a need for assistance in Wave II and of those caregivers that identified a need for assistance only 25% in Wave I and 14% in Wave II reported assistance with management of fatigue. Similar results are true for the symptom of pain, 48% of caregivers identified a need for assistance in Wave I and 34% identified a need for assistance in Wave II and of those that reported a need for assistance, 29% in Wave I and 47% in Wave II report assistance with management of pain. Research supports these findings, in a study by Siegel et al. (1991) 483 patients with cancer and their informal caregivers were studied. Earlier discussion suggests that the symptoms of fatigue and pain have direct implications on the overall well being of the patient. It would be of particular importance to study this implication further. The advanced practice nurse must diligently work with the patient and caregiver to devise a plan to assist caregivers with complex symptom management.

The independent variable of gender proved to be 2. significant in regards to caregiver reports of need for assistance with ADL's/IADL's. From the regression, (Pvalue of 0.0012) and (Odds ratio 0.043) suggests males are more likely to be independent than females (see Table 6). This holds true in both Wave I and Wave II data. Literature supports these findings. In a study involving 596 patients, Mor et al. (1994) found that males have a significantly lower rate of functional decline than females (18.5% vs. 31.8%). Similarly, of 596 patients studied by Guadagnoli, Rice, and Mor, (1991), women patients were 7.8 times more likely to use formal services than men patients. This should be of particular importance to the advanced practice nurse in the initial planning stages for caregiver involvement of ADL's/IADL's. This study suggests that women will need more assistance, however further research is needed.

In summary, from this study, it would appear that caregiver involvement for elderly colorectal cancer patients consists of assistance with housework, laundry and transportation in ADL's/IADL's. Symptom management focuses on the management of nausea, poor appetite, diarrhea, fatigue and pain and assistance in health care activities is limited but focuses on the assistance with oral medications. The results of this study indicate that according to the caregivers of patients with colorectal cancer the Activities of Symptom Management Assistance are needed most frequently, followed by the Activities of Daily Living Assistance and the least assistance is needed with Activities of Health Care Activities. The independent variables of stage of disease, patient comorbidity and interval of time in treatment proved to be non-significant in this study. However, due to the small sample size, generalizing to a larger population should be done with caution.

Discussion of Results within the Conceptual Framework The results of this study are unable to support the Caregiver Model from Given and Given (1995), by suggesting the Nature of the Cancer and Care Situation (care requirements) influence the Demands on Caregiver and Patient (patient activities of daily living/instrumental activities of daily living, patient symptom experience, and health care activities). In accordance with Given and Given, (1995) conceptualization of the caregiver model and the literature review based on this topic, one would predict that the independent variables of stage of the cancer, patient comorbidity, and interval of time in treatment would impact the Demands on Caregiver and Patient. In this analysis, that did not happen. This researcher failed to show the significance of the independent variables, stage of the cancer, patient comorbidity, and interval of time in treatment as they relate to Demands on Caregiver and Patient referred to in this study as caregiver involvement. However, this study did identify general areas of caregiver

involvement and also specific tasks of care as they relate to colorectal cancer patients.

It is suggested that the same model and statistical techniques be applied to a larger sample. In this way, interaction effects can better be examined and caregiver involvement in specific tasks of care for elderly, colorectal cancer patients can be determined. Also suggested is to use the same model in testing the difference of patient report of a need for assistance and patient report of assistance given versus caregiver report of patient requiring assistance and caregiver report of assistance given. This information could aid the advanced practice nurse in determining actual unmet needs to assist the patient and caregiver with anticipatory guidance regarding actual home care needs. This information could also assist the advanced practice nurse in developing appropriate assessment tools and educational materials for both elderly cancer patients and their family caregivers.

Implications for Advanced Practice Nurses

Colorectal cancer is the fourth most prevalent carcinoma and the second most frequent cause of death from cancer in the United States. Cancer is a disease that presents itself in people of all ages, however colorectal cancer specifically targets the elderly, occurring in men and women in equal numbers. Incidence increases steadily after age 40 and to the ninth decade. Colorectal cancer is one of the three leading cancer sites in people over the age

of 65. By the year 2030 it has been estimated that those over the age of 65 will represent 15-18% or as high as 21% of the population (U.S. Bureau of the Census, Current Population Reports, 1984). Health care services previously provided within acute care settings are increasingly becoming the responsibility of patients and their caregivers in home care settings.

As Medicare patients are placed into the managed care environment, the advanced practice nurse will be expected to assume greater responsibility for elderly patients in the managed care setting to provide cost effective, competent This study reveals a population of elderly, care. colorectal cancer patients, a majority of them experiencing one or more comorbidity and nearly half with late stage disease. Many of the caregivers of these patients are elderly spouses, possibly facing health problems of their own. Nearly half of these patients are receiving chemotherapy treatment by Wave II. The advanced practice nurse is in a unique position to assist the elderly cancer patient and family caregivers in the development of appropriate strategies that facilitate the management of this health care. The need to utilize advanced practice nurses as resources in this population is increasingly evident due to the needed assessment skills for both physical and psychosocial needs, case managing and collaborating expertise with all involved health care professionals, and the capacity for the advanced practice

nurse to advocate for patients and their family during their cancer experience.

A comprehensive assessment of the patient and caregiver's knowledge, expectations, and needs are an essential first step in assisting the family during their cancer experience. Assessment of a patient/caregiver's knowledge and expectations should include evaluation of information given to the family at the time of diagnosis of colorectal cancer and their understanding of the information. Any deficits noted in these areas should be addressed by the advanced practice nurse.

The advanced practice nurse must assess the likelihood of the patient to require assistance with ADL's or IADL's. Once limitations are ascertained, the advanced practice nurse must be clear and present the patient and caregiver a specific task list (i.e. bathing, eating, dressing, toileting, walking inside the home, transferring in and out of bed, laundry, cooking, housework, shopping and transportation) to determine which activities are limited. This information will be helpful to the advanced practice nurse in anticipating the needs of colorectal cancer patients and their caregivers prior to discharge from the acute care setting.

The activities of daily living assistance category identifies the functional disabilities of the patient from disease and treatment that impact self-care and instrumental activities of daily living. According to the findings of

this study, assessment should include exploring assistance in all of the instrumental activities of daily living, especially housework, laundry and transportation. It is important to adequately assess this category of care with these patients and their caregivers. Interventions for limitations in ADL's and IADL's begin immediately after surgery. The advanced practice nurse must continue to assess the patient's performance in preparation to be discharged from the hospital. After discharge, continuous monitoring of the aforementioned task list will be beneficial to track the patients' progress or the caregivers' awareness of increased need for caregiver involvement. The results of this study show that housework, laundry and transportation are three of the ADL's/IADL's requiring caregiver involvement.

The advanced practice nurses' assessment of the patients' perception of their needs versus the caregivers' perception of patient needs is another important factor to consider. If the perceptions of the patient and the caregiver do not match, the advanced practice nurse should act as advocate/counselor to help the patient express the needs to the caregiver. In this manner, the advanced practice nurse should assess the caregiving situation to help the patient/caregiver dyad to set mutual goals to aid in communication to prevent the patient and the caregiver from feeling overburdened, overwhelmed or neglected. A continuous assessment of this situation is important to gain

information on the full range of activities and the extent of patient needs versus caregiver involvement in each area of the demands of care. If it is found that the caregivers are not assisting the patient due to lack of knowledge, the advanced practice nurse could aid the patient and caregiver in devising a plan of intervention that will be of benefit to both the patient and the caregiver.

This study reveals that caregivers are themselves elderly. Nearly two thirds (65%) of the caregivers are over the age of sixty. Many of the caregivers may be retired. However, the age of the caregivers, (32%) are ages 30-59 years old, indicates that some may still be employed outside of the home. The competing roles of the caregiver may come into play in this situation. Planning for the caregivers' competing roles in advance may help limit stress and feelings of inadequacy in the patient and the caregiver once the patient is discharged.

If patients are told that many people that have this same diagnosis and surgery have found it helpful to have assistance with housework, laundry and transportation, the patient may be given permission to realize it is normal to need help. The results of this study suggest that caregiver involvement in ADL's/IADL's decreases by Wave II. As previously mentioned, the results of this study also suggest that caregiver involvement with symptom management is greater than caregiver involvement with ADL's/IADL's. However, as coordinator of care, the advanced practice nurse

must be familiar with the community resources and assist the patient and family by making appropriate referrals to other services as needed. Service referrals might be appropriately made to obtain meals, chore services, assistance with personal care, and respite care for the caregiver. By arranging the referrals initially, the advanced practice nurse is actually relieving some of the caregivers burden by suggesting it is okay to need help. Thus, the competing roles of the caregiver may not bring about so much guilt if these tasks can be provided by someone outside of the home. Within the context of limited health care budgets referrals that are suitable may ultimately save the caregivers limited time and both the patient and the caregivers limited monetary resources.

The results of this study have found that at least one fourth of the caregivers were involved with the management of fatigue, pain, diarrhea, trouble sleeping, nausea, and poor appetite at the time of initial diagnosis. Caregiver involvement in several of these categories decreased slightly, however, caregiver involvement in the management of pain increased. It makes sense that symptom management would continue to be an issue to health care providers. It would seem with good management, pain should be under control by Wave II. It is imperative that a thorough history should be taken of all the symptoms the patient has been experiencing. This should include information regarding when the symptom started, how long it lasts,

aggravating and alleviating factors, the current home management treatment for the symptom and if the symptom was present before the diagnosis of cancer.

After the patient's symptom assessment is completed, the advanced practice nurse can then assist the patient and caregiver in symptom control through timely interventions and instruction on home management to diminish the severity of these symptoms. The advanced practice nurse should provide the patient and the caregiver with information handouts on several of the most frequently experienced symptoms. The handouts should be easy to read, concise and should include symptoms, interventions, what to avoid, and when to call the health care professional for assistance. This information is valuable and may help prevent patient complications and decrease patient/caregiver stress. Continuous evaluation of the symptoms experienced and tracking on a severity scale of 1-10 is imperative to evaluate success of the interventions and make changes to the plan of care as needed. Open lines of communication should be established between the advanced practice nurse and the caregiver. The advanced practice nurse could encourage the caregiver to be in direct contact with the health care team, which would allow the caregiver to seek advice on how to proceed if previous measures have failed to relieve the symptoms.

The results of this study show that 25% of caregivers are involved in the management of fatigue. Given the fact

that half of these elderly patients are experiencing late stage disease and by Wave II nearly half are receiving chemotherapy treatment it comes as no surprise that caregivers are involved with the management of fatigue. Fatigue can be a vague complaint and may be the result of trouble sleeping, pain, difficulty concentrating etc. or it may lead to complaints of these symptoms. The advanced practice nurse must initially provide the family with information that this symptom is commonly experienced by patients with colorectal cancer and can be possibly diminished with the help of family and friends. Providing the patient and family with methods of assisting the patient with their fatigue may include incorporating rest periods during the day and scheduling physician visits or treatments during the time of day that the patient has the most energy.

The advanced practice nurse should also encourage the patient and caregiver to schedule necessary activities throughout the day rather than all at once. Encouraging family and friends to assist with activities such as housework, shopping and cooking or preparing meals frees the patient from daily activities and promotes rest time. The advanced practice nurse must also discuss with the patient and the caregiver the importance of accepting help from family and friends. Accepting the offered help will not only assist the patient and caregiver in coping with this complex symptom of fatigue, it is also a way for family members and friends to participate in the patient's cancer

care and have a sense of helping their loved ones during this difficult time. The advanced practice nurse, through empathetic understanding, must relate to the patient and the caregiver that following surgery and during the treatment phase the patients' complaint of fatigue may not be completely resolved. Informing the patient and caregiver immediately regarding this matter may help alleviate patient and caregivers' concerns. This information may also normalize the situation so the patient and caregiver expect this symptom to persist and attempt to manage their activities of daily living accordingly.

The advanced practice nurse must be ready to direct the care of the patient in regards to specific health care activities. The results of this study shows caregiver involvement with such health care activities as oral medications, skin care, injections and enemas during the course of the disease. Initially, the need for home health nurses to help in the education of performing specific tasks may be necessary. This will allow the needed time for the patient and caregiver to become familiar with the procedure and acquire the confidence needed to perform these specific tasks. If the caregiver is prepared for the role this will alleviate caregiver burden. Home health nurses can assess the caregivers' preparedness level and develop a plan to increase the caregivers' knowledge and improve the caregivers' skills needed to perform tasks relating to health care activities.

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 advanced practice nurse needs to support the patients' decision 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. This study suggests that female patients will be more dependent than their male counterparts in ADL's/IADL's, the advanced practice nurse must keep this in mind when planning for the care of the individual patients. This finding may only suggest that males are less likely to admit that they need help. The advanced practice nurse must be attuned to this possibility and develop the plan of care as necessary. The caregivers need anticipatory guidance regarding the changes that can occur in the patients functional status and how their role will change. The caregiver also needs to be informed of other tasks of care that may be required of them during the course of the disease such as oral medication and skin care.

The advanced practice nurse can provide emotional support for both the patient and caregiver. Exploring past

coping mechanisms and current strategies allows a unique opportunity to provide the patient and caregiver with lifelong coping strategies which might include relaxation techniques, journal writings, humor therapy, or music therapy that will aid in their ability to cope with their current situation. The advanced practice nurse is in a unique position to offer these alternative therapies to compliment the patient's medical regime. Also, if patients with cancer are to receive the best care possible, the advanced practice nurse must enlist their family caregivers as partners in this care. Assessing caregiver needs and providing interventions for caregivers related to those needs are imperative.

Knowledge of the need for caregiver involvement in elderly colorectal cancer patients will allow the advanced practice nurse to make appropriate recommendations to congress persons, senators and support current legislation. The advanced practice nurse should work with the cancer community to develop a legislative agenda that can be used by organizations and national associations to ensure that public policies are favorable to accessing quality cancer care. The role of the advanced practice nurse as policy maker is closely related to the role of the advanced practice nurse as researcher. Understanding the needs of a patient population through research based knowledge will assist the advanced practice nurse in developing interventions specific to individual needs.

By placing emphasis on holistic health care, the advanced practice nurse can take into consideration all aspects of the patient in developing care interventions. The value of determining the need for caregiver involvement of the elderly colorectal cancer patients lies not only in providing adequate care to the patient, but in assisting the caregiver to manage during a difficult time, and in the allocation of limited health care services. Use of critical thinking skills, setting mutual goals, anticipatory guidance, alternative therapies and empathetic understanding will allow the advanced practice nurse to assist patients and their family caregivers in determining areas of caregiver involvement for elderly colorectal cancer patients.

Implications for Further Research

The literature review, as delineated previously, revealed little research has been conducted examining colorectal cancer patients and specific tasks of caregiver involvement. Determining caregiver involvement in specific tasks of care of colorectal cancer patients is difficult with such a small sample size (n=48). However, opportunities for further research remain. Therefore, suggestions for further research include:

 a) Extended research using the same model and statistical techniques in a larger patient population, from the same data base and observe changes over time.

Incorporating all colorectal cancer dyads involved in the initial study through Wave IV may reveal more statistical significance in all independent variables.

- b) A study that examines the amount of caregiver involvement required in elderly cancer patients with different diagnosis (i.e. colorectal, lung, breast, and prostate) may be helpful to determine the caregiving requirements of many elderly cancer patients.
- c) A qualitative study that allows focus groups to share the what they need or would want to know, in regard to initial education for patient and caregiver -- what to expect regarding the colorectal cancer diagnosis and treatment regime (i.e. how to deal with fatigue and pain management, etc.)
- d) Research into development of a screening tool to assess elderly cancer patients needs in the three categories of care including ADL's/IADL's, symptom management, and health care activities, that could be used on an ongoing basis to reevaluate the needs of the patient throughout the course of the disease.

The need for increasing research based knowledge is evident in today's changing health care market. Gone are the days when nurses could justify their actions by the fact that it was always done that way. The advanced practice nurse must remain on the cutting edge in the health care arena by striving to deliver cost effective care to patients and families that are more informed than ever before regarding choices in their care. It is through sound nursing research that this task will be accomplished.

Summary

This study focused on caregiver involvement including specific tasks of care needed in the elderly colorectal cancer patient. Independent variables that proved to be statistically significant were males were more likely to be independent in ADL's/IADL's and symptom management. This study was unable to determine a relationship between the independent variables of stage of disease, patient comorbidity, and interval of time in treatment with caregiver involvement.

It appears the needs of the elderly will continue to increase as the cohort lives longer and grows larger in number. It is crucial that current researchers continue to study the needs of this population to provide appropriate care. This study has identified many specific tasks of care required by elderly colorectal cancer patients. It is with this knowledge that advanced practice nurses can provide anticipatory guidance in the types of caregiving that will be required along the continuum of cancer care.

Advanced practice nurses must assume the lead role in delivering researched based, collaborative care within an ever changing marketplace. Advanced practice nurses, as

clinicians, collaborators, advocates, and educators must position themselves to proactively respond to the needs of the elderly and lead other health care professionals in providing comprehensive care.

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APPENDIX A

ID	 	/INT	
DATE	 _/	_/_	

PHYSICAL HEALTH PATIENT

Following are a list of illnesses individuals often have. Please indicate if you have been diagnosed by a health care professional (HCP) that you <u>CURRENTLY HAVE THIS ILLNESS</u>. We are interested in knowing the illnesses you have now in addition to cancer. (check one for each condition)

1. Has a health care professional ever told you that you have high blood pressure or hypertension? (check one)

____Yes (1) ____No (2) ____DK/NA/Refused (9)

- 2. Has a health care professional every told you that you have diabetes? (check one)
 - ____ Yes (1) ____ No (2) ____ DK/NA/Refused (9)
- 3. Has a health care professional ever told you that you have cancer or a malignant tumor, other than the cancer for which you currently are being treated? (check one)
 - _____Yes (1) _____No (2) _____DK/NA/Refused (9)
- 4. In which organ or part of your body did your (most recent) cancer start? (write in)
- 5. Not including asthma, has a health care professional ever told you that you have chronic lung disease such as chronic bronchitis or emphysema? (check one)

_____Yes (1) _____No (2) _____DK/NA/Refused (9)

6. Has a health care professional ever told you that you had a heart attack, coronary heart disease, angina, congestive heart failure, or other heart problems? (check one)

____ Yes (1) ____ No (2) ____ DK/NA/Refused (9)

7. Has a health care professional ever told you that you had a stroke? (check one)

_____Yes (1) _____No (2) _____DK/NA/Refused (9)

(GO TO NEXT PAGE)

ID _____/INT ___ Date ___/___/___

 Have you ever seen a health care professional for emotional, nervous, or psychiatric problems? (check one)

Yes (Go to 8a) (1) No (Go to 9) (2) DK/NA/Refused (9)

Sa. Have you had any of these problems in the last 12 months? (check one)

_____ Yes (1) _____ No (2) ____ DK/NA/Refused (9)

 During the last 12 months, have you seen a health care professional specifically for arthritis or rheumatism? (check one)

> _____Yes (1) _____No (2) _____DK/NA/Refused (9)

10. Have you ever fractured your hip? (check one)

____ Yes (1) ____ No (2) ____ DK/NA/Refused (9)

The next question might not be easy to talk about, but it is very important for research on health and aging.

11. During the last 12 months, have you lost any amount of urine beyond your control? (check one)

____Yes (1) ____No (2) ____DK/NA/Refused (9)

12. With or without corrective lenses, would you consider your eyesight to be excellent, very good, good, fair, or poor? (check one)

____ Excellent (1)
____ Very good (2)
____ Good (3)
____ Fair (4)
____ Poor (5)
____ DK/NA/Refused (9)

13. Have you ever had cataract surgery? (check one)

____ Yes (1) ____ No (2) ____ DK/NA/Refused (9) APPENDIX B

NINR/NCI WAVE II CAREGIVER W/O PATIENT TELEPHONE

ID _____/INT ____

The next set of questions addresses the 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 <u>from</u> bed clothing into the set of clothing worn during the day, and change to bed clothing at night. This category DOES MOT include management of clothing during toileting. If your ______ wears bed clothing during the day, answer "IS NEVER DRESSING. Select the category that best describes your ______'s level of functioning for DRESSING.

1a. With regard to dressing, would you say that your _____ ... (check one)

- ____ IS INDEPENDENT (does not need help of another person in any part of this activity) (Go to question 2) (1)
- _____ MEEDS SUPERVISION COLY (requires another person present during activity to watch the patient in case of problems - does not regularly assist) (Go to 1b) (2)
- _____ MEEDS SOME PHYSICAL HELP (requires physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATES (Go to 1b) (3)
- ____ MEEDS TOTAL PHYSICAL HELP (needs another person to carry out this activity) CARE RECIPIENT DOES NOT PARTICIPATE (Go to 1b) (4)
- IS NEVER DRESSED (Go to 2) (5)
- MA/REFUSED (9)
- 1b. Is the reason for this help related to your _____'s ... (check one)

Cancer or cancer treatment (Go to 1c) (1) Other health problem(s) (Go to 1c) (2) NA/Refused (9)

ic. If someone helps your _____ with dressing, who helps ... (check all that apply)

 you (primary caregiver (1) (Go to 1d)		unpaid family (5) (Go to le)
 paid family (2) (Go to 1f)	_	unpaid friends/others (6) (Go to le)
 paid friends/others (3) (Go to 1f)		unpaid professional (7) (Go to le)
 paid professional (4) (Go to 1f)		NA/Refused (9)

ld. If you (primary caregiver) help with dressing ...

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

_____ Times per week

(GO TO NEXT PAGE)

NINK/NCI WAVE II CAREGIVER W/O PATIENT TELEPHONE

ID____/INT____

(2) Approximately how long in minutes each time did you help with dressing? (write in)

____ Minutes each time

(Interviewer: If caregiver doesn't know, then ask them to estimate as best they can.)

le. If other unpaid helpers (family, friends, or professionals) help with dressing ...

(1) In the past week, how many times did these unpaid others help with dressing? (write in)

_ Times per week

(2) Approximately how long in minutes each time did these unpaid others help with dressing? (write in)

_____ Minutes each time

(Interviewer: If caregiver doesn't know, then ask them to estimate as best they can.)

1f. If other paid helpers (family, friends, or professionals) help with dressing ...

 In the past week, how many times did these paid others help with dressing? (write in)

__ Times per week

(2) Approximately how long in minutes each time did these paid others help with dressing? (write in)

____ Minutes each time

(Interviewer: If caregiver doesn't know, then ask them to estimate as best they can.)

(GO TO HELT PAGE)

NINR/NCI	WAVE II CAREGIVER W/O PATIENT TELEPHONE	ID/INT
2. EXTING:	This category includes all types of food and liquid taken all types of presentation used - tray, finger foods, etc. utensils. This does not include selection or preparation	by mouth. This includes ; you do not need to use of food.
2a. Wit	h regard to eating, would you say that your	(check one)
_	IS INDEPENDENT - (does not need help of another person in this activity) (Go to question 3) (1)	any part of
	MERDS SUPERVISION ONLY - (requires another person present to watch the patient in case of problems - does not regul (Go to 3b) (2)	during activity Larly assist)
	MEEDS SOME PHYSICAL HELP - (requires physical help and the another during all or part of this activity) CARE RECIPI (Go to 2b) (3)	ne presence of LENT PARTICIPATES
	MEEDS TOTAL PHYSICAL HELP - (needs another person to carr CARE RECIPIENT DOES NOT PARTICIPATE (Go to 2b) (4)	ry out this activity)
	NOT APPLICABLE - (needs tube feedings, IV's OHLT) (Go to	5) (5)
	KA/REFOSED (9)	
2b. Is	the reason for this help related to your's (check one)
	Cancer or cancer treatment (Go to 2c) (1) Other health problem(s) (Go to 2c) (2) NA/Refused (9)	
2c. If	someone helps your with eating, who helps (c	heck all that apply)
	you (primary caregiver (1) (Go to 2d) unpaid fami paid family (2) (Go to 2f) unpaid frie paid friends/others (3) (Go to 2f) unpaid prof paid professional (4) (Go to 2f) NA/Refused	lly (5) (Go to 2e) ands/others (6) (Go to 2e) essional (7) (Go to 2e) (9)
2d. If	you (primary caregiver) help with eating	
	(1) In the past week, how many times did you help with ear	ting? (write in)
	Times per week	
	(2) Approximately how long in minutes each time did you h (write in)	elp with eating?
	Minutes each time	
(Inter	viewer: If caregiver doesn't know, then ask them to estima	te as best they can.)
	(GO TO NEXT PAGE)	

NINR,	/NCI	WAVE	II	CAREGIVER	w/o	PATIENT	TELEPHONE	

ID____/INT____

2e. If other unpaid helpers (family, friends, or professionals) help with eating ...

 In the past week, how many times did these unpaid others help with eating? (write in)

____ Times per week

(2) Approximately how long in minutes each time did these unpaid others help with eating? (write in)

_____ Minutes each time

(Interviewer: If caregiver doesn't know, then ask them to estimate as best they can.)

- 2f. If other paid helpers (family, friends, or professionals) help with eating ...
 - In the past week, how many times did these paid others help with eating? (write in)

____ Times per week

(2) Approximately how long in minutes each time did these paid others help with eating? (write in)

____ Minutes each time

(Interviewer: If caregiver doesn't know, then ask them to estimate as best they can.)

- 3. BATHING: This category includes all activities of bathing, whether tub or shower or bed bath, such as entry into tub or shower, wetting, scaping, 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. With regard to bathing, would you say that your _____ ... (check one)
 - ____ IS INDEPENDENT (does not need help of another person in any part of this activity) (Go to question 4) (1)
 - _____ MEEDS SUPERVISION ORLY (requires another person present during activity to watch the patient in case of problems - does not regularly assist) (Go to 3b) (2)
 - _____ MEEDS SOME PHYSICAL HELP (requires physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATES (Go to 3b) (3)
 - ____ NEEDS TOTAL PHYSICAL HELP (needs another person to carry out this activity) CARE RECIPIENT DOES NOT PARTICIPATE (Go to 3b) (4)

____ MA/REFUSED (9)

NINR/NCI WAV	E II CAREGIVER W/O PATIENT TELEPHONE	ID/INT DATE7/
3b. Is the	reason for this help related to your	's (check one)
	acer or cancer treatment (Go to 3c) (1) Ser health problem(s) (Go to 3c) (2) /Refused (9)	
3c. If some	some helps your with bathing, who	helps (check all that apply)
	Du (primary caregiver) (1) (Go to 3d) aid family (2) (Go to 3f) aid friends/others (3) (Go to 3f) aid professional (4) (Go to 3f)	unpaid family (5) (Go to 3e) unpaid friends/others (6) (Go to 3e) unpaid professional (7) (Go to 3e) MA/Refused (9)
3d. 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	
(2)	Approximately how long in minutes each ti (write in)	me did you help with bathing?
	Minutes each time	
(Interview	er: If caregiver doesn't know, then ask th	en to estimate as best they can.)
3e. If oth	er unpaid helpers (family, friends, or pro	fessionals) help with bathing
(1)	In the past week, how many times did then (write in)	se unpaid others help with bathing?
	Times per week	
(2)	Approximately how long in minutes each t: bathing? (write in)	ime did these unpaid others help with
	Minutes each time	
(Interview	ar: If caregiver doesn't know, then ask the	ben to estimate as best they can.)
3f. If oth	er paid helpers (family, friends, or profe	ssionals) help with bathing
(1)	In the past week, how many times did the (write in)	se paid others help with bathing?
	Times per week	
(2)	Approximately how long in minutes each t bathing? (write in)	ime did these paid others help with
	Minutes each time	
(Interview	mer: If caregiver doesn't know, then ask t	hem to estimate as best they can.)

NINR/NCI WAVE II CAREGIVER W/	O PATIENT TELEPRONE	ID	7/10#T
4. WALKING INSIDE THE HOUSE:	This category includes all thouse. MUST MOVE AT LEAST F crutches, or handrail. Sele your's level of fur house.	upright movement on foot IVE FEET. May use cane, of the response that be actioning for walking in	: inside the walker, st describes iside the
4a. With regard to walkin (check one)	g inside the house, would you	u say that your	_ •••
IS DEPREDENT - activity) (Go to	(does not need help of anoth o question 5) (1)	wer person in any part o	f this
to watch the pat: (Go to 4b) (2)	f OHLY - (requires another pe lent in case of problems - do	erson present during act tes not regularly assist	ivity ;)
another during a (Go to 4b) (3)	CAL HELP - (requires physical 11 or part of this activity)	help and the presence CARE RECIPIENT PARTICI	of Pates
CARE RECIPIENT D	ICAL HELP - (needs another po DES NOT PARTICIPATE (Go to 4	irson to carry out this ib) (4)	activity)
IS UNABLE TO WALL	K - (will not bear weight)	(Go to 5) (5)	
NA/REFUSED (9)			
4b. Is the reason for thi	s help related to your	's (check one)	
Cancer or cancer Cher health prob MA/Refused (9)	treatment (Go to 4c) (1) lem(s) (Go to 4c) (2)		
4c. If someone helps your (check all that appl	with walking insid	e the house, who helps .	
you (primary care paid family (2) paid friends/othe paid professional	giver) (1) (Go to 4d)	unpaid family (5) (Go unpaid friends/others unpaid professional (7) NA/Refused (9)	to 4e) (6) (Go to 4e)) (Go to 4e)
4d. If you (primary careg	iver) help with walking insi	de the house	
(1) In the past w (write in)	sek, how many times did you h	elp with walking inside	the house?
	Times per week		

(2) Approximately how long in minutes each time did you help with walking inside the house? (write in)

_____ Minutes each time

(Interviewer: If caregiver doesn't know, then ask them to estimate as best they can.)

ID _____/INT ____ ID

4e. If other unpaid helpers (family, friends, or professionals) help with walking ...

(1) In the past week, how many times did these unpaid others help with walking inside the house? (write in)

Times per week

(2) Approximately how long in minutes each time did these unpaid others help with walking inside the house? (write in)

____ Minutes each time

(Interviewer: If caregiver doesn't know, then ask them to estimate as best they can.)

- 4f. If other paid helpers (family, friends, or professionals) help with walking inside the house ...
 - (1) In the past week, how many times did these paid others help with walking inside the house? (write in)

____ Times per week

(2) Approximately how long in minutes each time did these paid others help with walking inside the house? (write in)

Minutes each time

(Interviewer: If caregiver doesn't know, then ask them to estimate as best they can.)

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. With regard to toileting, would you say that your _____ ... (check one)

- ____ IS DECEMBERT (does not need help of another person in any part of this activity) (Go to question 6) (1)
- ____ MEEDS SUPERVISION ONLY (requires another person present during activity to watch the patient in case of problems - does not regularly assist) (Go to 5b) (2)
- _____ MEEDS SOME PHYSICAL HELP (requires physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATES (Go to 5b) (3)
- ____ MEEDS TOTAL PHYSICAL HELP (needs another person to carry out this activity) CARE RECIPIENT DOES NOT PARTICIPATE (Go to 5b) (4)
- ____ NOT APPLICABLE (has catheter, colostomy) (Go to 6) (5)
- ____ NA/REFUSED (9)

NINR/NCI WAVE	II CAREGIVER W/O PATIENT TELEPHONE	ID/INT DATE//
5b. Is the	reason for this help related to your	_'s (check one)
Cance Other NA/Re	er or cancer treatment (Go to 5c) (1) r health problem(s) (Go to 5c) (2) efused (9)	
5c. If some	one helps your with toileting, who	helps (check all that apply)
yo pa pa	u (primary caregiver) (1) (Go to 5d) id family (2) (Go to 5f) id friends/others (3) (Go to 5f) id professional (4) (Go to 5f)	unpaid family (5) (Go to 5e) unpaid friends/others (6) (Go to 5e) unpaid professional (7) (Go to 5e) NA/Refused (9)
5d. If you	(primary caregiver) help with toileting	
(1)	In the past week, how many times did you he	alp with toileting? (write in)
	Times per week	
(2)	Approximately how long in minutes each time (write in)	e did you help with toileting?
	Minutes each time	
(Interviewe	r: If caregiver doesn't know, then ask the	a to estimate as best they can.)
5e. If othe	r unpaid helpers (family, friends, or profe	ssionals) help with toileting
(1)	In the past week, how many times did these (write in)	unpeid others help with toileting?
	Times per week	
(2)	Approximately how long in minutes each tim toileting? (write in)	e did these unpaid others help with
	Minutes each time	
(Interview	r: If caregiver doesn't know, then ask the	m to estimate as best they can.)
5f. If othe	or paid helpers (family, friends, or profess	sionals) help with toileting
(1)	In the past week, how many times did these (write in)	paid others help with toileting?

_____ Times per week

(2) Approximately how long in minutes each time did these paid others help with toileting? (write in)

_____ Minutes each time

(Interviewer: If caregiver doesn't know, then ask them to estimate as best they can.)

NINR/NCI WAVE II CAREGIVER	W/O PATIENT TELEPHONE	ID/INT DATE//				
6. TRANSPERRING IN AND OUT	OF BED: This categor chair or who mechanical a best describ	y includes movement to and from bed, to belchair. Devices, bars, and other ids may be used. Select the response that bes your's level of independence.				
<pre>6a. With regard to trans (check one)</pre>	sferring in and out of bed	, would you say that your				
IS INDEPENDENT this activity)	- (does not need help of a (Go to question 7) (1)	mother person in any part of				
Left to watch the part (Go to 6b) (2)	CON CHILY - (requires anothe stient in case of problems	ar person present during activity - does not regularly assist)				
AREDS SOME PHY another during (Go to 6b) (3)	ICAL HELP - (requires phy all or part of this activ	sical help and the presence of ity) CARE RECIPIENT PARTICIPATES				
CARE RECIPIENT	MEEDS TOTAL PEYSICAL HELP - (needs another person to carry out this activity) CARE RECIPIENT DOES NOT PARTICIPATE (Go to 6b) (4)					
REGAINS BEDFAS	[(Go to 7) (5)					
MA/REFUSED (9)					
6b. Is the reason for t	his help related to your _	's (check one)				
Cancer or cancer Other health pro NA/Refused (9)	treatment (Go to 6c) (1 blem(s) (Go to 6c) (2)	.)				
6c. If someone helps yo (check all that ap	ur with transferm ply)	ing in and out of bed, who helps				
you (primary o paid family (2 paid friends/c paid friends/c paid professio	aregiver) (1) (Go to 6d)) (Go to 6f) thers (3) (Go to 6f) nal (4) (Go to 6f)	<pre>unpaid family (5) (Go to 6e) unpaid friends/others (6) (Go to 6e) unpaid professional (7) (Go to 6e) NA/Refused (9)</pre>				
6d. If you (primary car	egiver) help with transfer	rring in and out of bed				
(1) In the past of bed? (week, how many times did write in)	you help with transferring in and out				
	Times per week					
(2) Approximate and out of	ly how long in minutes eac bed? (write in)	h time did you help with transferring in				
	Minutes each time					

(Interviewer: If caregiver doesn't know, then ask them to estimate as best they can.)

•

NINR/NCI WAVE II CAREGIVER W/O PATIENT TELEPHONE	ID/INT DATE7/
6e. If other unpaid helpers (family, friends, or profe in and out of bed	essionals) help with transferring
 In the past week, how many times did these in and out of bed? (write in) 	unpaid others help with transferring

____ Times per week

(2) Approximately how long in minutes each time did these unpaid others help with transferring in and out of bed? (write in)

___ Minutes each time

(Interviewer: If caregiver doesn't know, then ask them to estimate as best they can.)

- 6f. If other paid helpers (family, friends, or professionals) help with transferring in and out of bed ...
 - (1) In the past week, how many times did these paid others help with transferring in and out of bed? (write in)

____ Times per week

(2) Approximately how long in minutes each time did these paid others help with transferring in and out of bed? (write in)

_____ Minutes each time

(Interviewer: If caregiver doesn't know, then ask them to estimate as best they can.)

7. TRANSPORTATION

- 7a. 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)
 - ____ DRIVES HIMSELF/HERSELF (did not need help of another person) (1)
 - MEEDS SUPERVISION (required supervision and the presence of another during all or part of this activity) (2)
 - MEEDS SOME PHYSICAL HELP (needed another person to help drive occasionally) (3)
 - HEEDS TOTAL PHYSICAL HELP (needed others to drive) (4)
 - ____ NOT APPLICABLE (others have always done this) (9)
 - ____ MA/REFUSED (9)

(GO TO MEET PAGE)

ID _____/INT DATE ____7___/ NINR/NCI WAVE II CAREGIVER W/O PATIENT TELEPHONE ID 7b. Is the reason for this help related to your 's ... (check one) Cancer or cancer treatment (Go to 7c) (1) Other health problem(s) (Go to 7c) (2) NA/Refused (9) 7c. If someone helps your _____ with transportation, who helps ... (check all that apply) _ you (primary caregiver) (1) (Go to 7d) ____ unpaid family (5) (Go to 7e) _ paid family (2) (Go to 7f) ____ unpaid friends/others (6) (Go to 7c) _ paid friends/others (3) (Go to 7f) ____ unpaid professional (7) (Go to 7e) _ paid professional (4) (Go to 7f) ____ XA/Refused (9) _ (Go to 7e) 7d. 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 (2) Approximately how long in minutes each time did you help with transportation? (write in) _ Minutes each time (Interviewer: If caregiver doesn't know, then ask them to estimate as best they can.) 7e. If other unpaid helpers (family, friends, or professionals) help with transportation ... In the past week, how many times did these unpaid others help with transportation? (write in) (1) __ Times per week (2) Approximately how long in minutes each time did these unpaid others help with transportation? (write in) _ Minutes each time (Interviewer: If caregiver doesn't know, then ask them to estimate as best they can.) 7f. If other paid helpers (family, friends, or professionals) help with transportation ... (1) In the past week, how many times did these paid others help with transportation? (write in) ____ Times per week (2) Approximately how long in minutes each time did these paid others help with transportation? (write in) ___ Minutes each time (Interviewer: If caregiver doesn't know, then ask them to estimate as best they can.)

NINR/NCI WAVE II CAREGIVER W/O PATIENT TELEPHONE

ID _____/INT ____

8. LAUNDRY

8a. With regard to laundry, would you say that your ____ ... (check one)

- ____ IS INDEPENDENT (does not need help of another person in any part of this activity) (Go to question 9) (1)
- MENDS SUPERVISION CHLY (requires another person present during activity to watch the patient in case of problems - does not regularly assist) (Go to 8b) (2)
- MEEDS SOME PHYSICAL HELP (requires physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATES (Go to Sb) (3)
- _____ MEEDS TOTAL PHYSICAL HELP (needs another person to carry out this activity) CARE RECIPIENT DOES NOT PARTICIPATE (Go to 8b) (4)
- OTHERS HAVE ALMAYS DOME THIS (Go to 8b) (5)
- WA/REFUSED (9)

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

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

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

_____you (primary caregiver) (1) (Go to 8d) _____ unpaid family (5) (Go to 8e) ______unpaid family (2) (Go to 8f) ______unpaid friends/others (6) (Go to 8e) ______paid friends/others (3) (Go to 8f) ______unpaid professional (7) (Go to 8e) paid professional (4) (Go to 8f) NA/Refused (9)

8d. 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

(2) Approximately how long in minutes each time did you help with laundry? (write in)

Minutes each time

(Interviewer: If caregiver doesn't know, then ask them to estimate as best they can.)

- 8e. If other unpeid helpers (family, friends, or professionals) help with laundry
 - (1) In the past week, how many times did these unpaid others help with laundry? (write in)

_____ Times per week

NINR/NCI WAVE II CAREGIVER W/O PATIENT TELEPEONE

ID____/INT____

(2) Approximately how long in minutes each time did these unpaid others help with laundry? (write in)

Minutes each time

(Interviewer: If caregiver doesn't know, then ask them to estimate as best they can.)

8f. If other paid helpers (family, friends, or professionals) help with laundry ...

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

_ Times per week

(2) Approximately how long in minutes each time did these paid others help with laundry? (write in)

_ Minutes each time

(Interviewer: If caregiver doesn't know, then ask them to estimate as best they can.)

- 9. SHOPPING: Includes all types of purchases.
 - 9a. With regard to shopping, would you say that your _____ ... (check one)
 - IS INDEPENDENT (does not need help of another person in any part of this activity) (Go to question 10) (1)
 - NEEDS SUPERVISION ONLY (requires another person present during activity to watch the patient in case of problems - does not regularly assist) (Go to 9b) (2)
 - MEEDS SOME PHYSICAL HELP (requires physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATES (Go to 9b) (3)
 - MEEDS TOTAL PHYSICAL HELP -- (needs another person to carry out this activity) CARE RECIPIENT DOES NOT PARTICIPATE (Go to 9b) (4) ____
 - OTHERS HAVE ALWAYS DORE THIS (Go to 9b) (5)
 - NA/REFUSED (9)

9b. Is this help related to your ____ ____'s ... (check one)

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

(GO TO NEXT PAGE)

INR.	/NCI	WAVE I		TR W/O P	ATIENT	TELEPEON	E					ID DATE		<u>, </u>	/INT	-
9c.	If	someone	helps	your		with s	pobb	ing,	wbo	helps	•••	(check	all t	bat i	apply)	
		you (paid	primary family	caregi (2) (G	ver) (ko to 9	1) (Go f)	to	9d)		unpai unpai	d fam d fri	ily (5) ends/ot	(Go hers (to 9 6)	e) (Go to :	9e)
		paid paid	friends profess	/others ional ((3) (4) (g	(Go to o to 91	9£) :)			unpai MA/Re	d pro fused	fession (9)	al (7)	(a	o to 9e	5

9d. 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

Approximately how long in minutes each time did you help with shopping? (2) (write in)

___ Minutes each time

(Interviewer: If caregiver doesn't know, then ask them to estimate as best they can.)

9e. If other unpaid helpers (family, friends, or professionals) help with shopping ...

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

_ Times per week

(2) Approximately how long in minutes each time did these unpaid others help with shopping? (write in)

Minutes each time

(Interviewer: If caregiver doesn't know, then ask them to estimate as best they can.)

9f. If other paid helpers (family, friends, or professionals) help with shopping ...

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

_ Times per week

(2) Approximately how long in minutes each time did these paid others help with shopping? (write in)

Minutes each time

(Interviewer: If caregiver doesn't know, then ask them to estimate as best they can.)

(GO TO RELT PAGE)

NINR/NCI	WAVE II CAREGIVER W/O PATIENT TELEPHONE	ID/INT Date7/
10. HOUSE	WORK: This includes picking up, dusting, light cleaning, dishes.	vacuuming, or doing
10a. Wi	th regard to housework, would you say that your	(check one)
	IS DEDEPENDENT - (does not need help of another person in activity) (Go to question 11) (1)	any part of this
	MEEDS SUPERVISION ONLY - (requires another person present to watch the patient in case of problems - does not regul (Go to 10b) (2)	during activity arly assist)
	NEEDS SOME PERSICAL HELP - (requires physical help and the another during all or part of this activity) CARE RECIPI (Go to 10b) (3)	ne presence of Tent participates
	NEEDS TOTAL PHYSICAL HELP - (needs another person to carr CARE RECIPIENT DOES NOT PARTICIPATE (Go to 10b) (4)	ry out this activity)
	OTHERS HAVE ALMAYS DOME THIS (Go to 10b) (5)	
	NA/REFUSED (9)	
10b. Is	this help related to your's (check one)	
	Cancer or cancer treatment (Go to 10c) (1) Other health problem(s) (Go to 10c) (2) Others have always done this (Go to 10c) (3) NA/Refused (9)	
10c. If	f someone helps your with housework, who helps	. (check all that apply)
	you (primary caregiver) (1) (Go to 10d) unpaid fami paid family (2) (Go to 10f) unpaid frie paid friends/others (3) (Go to 10f) unpaid prof paid professional (4) (Go to 10f) NA/Refused	ly (5) (Go to 10e) nds/others (6) (Go to 10e) essional (7) (Go to 10e) (9)
10d. If	f you (primary caregiver) help with housework	
()	1) In the past week, how many times did you help with how	usework? (write in)
	Times per week	
(2	 Approximately how long in minutes each time did you h (write in) 	elp with housework?
	Minutes each time	
(Interv	iewer: If caregiver doesn't know, then ask them to estima	te as best they can.)

(GO TO NEXT PAGE)

NINR/NCI-WAVE II CAREGIVER W/O PATIENT TELEPHONE	ID	/
10e. If other unpaid helpers (family, friends, or professionals)	help with	housework

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

_ Times per week

(2) Approximately how long in minutes each time did these unpaid others help with housework? (write in)

____ Minutes each time

(Interviewer: If caregiver doesn't know, then ask them to estimate as best they can.)

- 10f. If other paid helpers (family, friends, or professionals) help with housework ...
 - In the past week, how many times did these paid others help with housework? (write in)

_ Times per week

(2) Approximately how long in minutes each time did these paid others help with housework? (write in)

____ Minutes each time

(Interviewer: If caregiver doesn't know, then ask them to estimate as best they can.)

11. COOKING AND PREPARING MEALS

- 11a. With regard to cooking and preparing meals, would you say that your _____ ...
 (check one)
 - ____ IS INDEPENDENT (does not need help of another person in any part of this activity) (Go to next section) (1)
 - ______ NEEDS SUPERVISION ONLY (requires another person present during activity to watch the patient in case of problems - does not regularly assist) (Go to 11b) (2)
 - _____ MEEDS SOME PHYSICAL HELP (requires physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATES (Go to 11b) (3)
 - _____ NEEDS TOTAL PHYSICAL HELP (needs another person to carry out this activity) CARE RECIPIENT DOES NOT PARTICIPATE (Go to 11b) (4)
 - OTHERS HAVE ALWAYS DOME THIS (Go to 11b) (5)
 - ____ NOT APPLICABLE (has tube feedings, IV's OMLY) (Go to next section) (6)
 - ____ NOA/REFUSED (9)

NINP/NCI WAVE II CAREGIVER W/O PATIENT TELEPHONE ID/INT Date/	
11b. Is this help related to your's (check one)	
Cancer or cancer treatment (Go to 11c) (1) Other health problem(s) (Go to 11c) (2) Others have always done this (Go to 11c) (3) MA/Refused (9)	
<pre>llc. If someone helps your with cooking and preparing meals, who helps (check all that apply)</pre>	
you (primary caregiver) (1) (Go to 11d) unpaid family (5) (Go to 11e) paid family (2) (Go to 11f) unpaid friends/others (6) (Go to 11 paid friends/others (3) (Go to 11f) unpaid professional (7) (Go to 11e) paid professional (4) (Go to 11f) NA/Refused (9)	•)
11d. If you (primary caregiver) help with cooking and preparing meals	
(1) In the past week, how many times did you help with cooking and preparing meals (write in)	17
Times per week	
(2) Approximately how long in minutes each time did you help with cooking and preparing meals? (write in)	
Minutes each time	
(Interviewer: If caregiver doesn't know, then ask them to estimate as best they can.)	
lle. If other unpaid helpers (family, friends, or professionals) help with cooking and preparing meals	
(1) In the past week, how many times did these unpaid others help with cooking and preparing meals? (write in)	i
Times per week	

(2) Approximately how long in minutes each time did these unpaid others help with cooking and preparing meals? (write in)

_____ Minutes each time

_

(Interviewer: If caregiver doesn't know, then ask them to estimate as best they can.)

(GO TO NEXT PAGE)

NINR/NCI WAVE II CAREGIVER W/O PATIENT TELEPHONE

ID____/INT____

11f. If other paid helpers (family, friends, or professionals) help with cooking and preparing meals ...

(1) In the past week, how many times did these paid others help with cooking and preparing meals? (write in)

_ Times per week

(2) Approximately how long in minutes each time did these paid others help with cooking and preparing meals? (write in)

____ Minutes each time

(Interviewer: If caregiver doesn't know, then ask them to estimate as best they can.)

(GO TO NEXT SECTION)

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2

9. Poor appetite. 1 2

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ID/INT DATE//	D. Total number of minutes in past two weeks?	(write in total minutes)		minutes	minutes	minutes	minutes	minutes	minutes	minutes	
	/one assist	NO (2)	one)	2	7	2	2	7	7	7	
	C. Did you/any patient?	YES (1)	(circle	1	-	1	t.	-	-	-	
ELEPHONE	of in past two	NO (2)	e one)	2	7	7	7	2	2	7	
W/O PATIENT TE	B. Complain c weeks?	YES (1)	(circl	-	-	-	-	-	-	-	
NINR/NCI WAVE II CAREGIVER	A. Symptom				10. Weight loss.	11. Fever.	12. Cough.	13. Dry mouth.	14. Constipation.	15. Frequent urination.	

(GO TO NEXT SECTION)

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	NINR/NCI WAVE II CAF	REGIVEF	3 w/o Patie	ent Telephone			_/INT
				ACTIVITIES OF HEAL	TH CARE		
- 1	he next set of questions in with cancer require	sthis t	health care a reatment or p	ctivities or treatments that your procedure, and then I will have add	with cancer may or may not requirional questions about how others help.	ilre. First I will ask	if your
	nterviewer: The following Ask sectiv	questior on A –	ns have three each item fo	ə sections: A, B, & C. ər all caragivers.			
	If answer in section A is If answer is section A is	s NO -	go to next lo go to sectlo	em (i.e., next health care activity). ins B & C.			
1				(MARK THE APPROPRIATE ANS	WERS FOR EACH)		
4	 Does your require any of the following treatments or procedures? 	YES YES NO	S Z Z Z Z	B. If YES, who helps your	C. In the past two weeks how mar how long in minutes each time	ny times and appro did it take to do th	kimately is task?
		(circi		caregiver) 2 = Paid family 3 = Paid friends/	If primary caregiver: If paid help: (choice #18) (#28,38,46	: If unpaid help (#58,68,:	
		onu	6	others 4 = Pald professional 5 = Unpald family 6 = Unpald friends/	_ times _ minutes _ times _ minu (write i	utes _ times _ mir in)	lutes
				others 7 = Unpaid professional	Interviewer: If more than one help. add all instances of h	er in each category heip together.	
				(circle all that apply)			
		-	2	1234587	_ times _ minutes _ times _ minut	tes _ times _ min	Ites
÷	Special exercises/phys. therapy.	-	ю	1234587	times minutes times minut	tes times min.	tes
ñ	Oral medications.	-	2	1234567	times minutes times minuto	ies times _ minu	tes

	VINR/NCI WAVE II CAREGI	VER V	ν/ο Ράτιε	T T	ELE	H	ONE									
٩	 Does your require any of the following treatments 	YES YES	N 1	α [']	=	YES	ا [™] ک	۲. ۲	helps your	C. In t hor	he past two v long in mi	weeki nutes (s how many t	imes and appr It take to do ti	oximately his task?	
	or procedures?	NO = (circle	ñ	90 -	- UCC	aid aid	(prir jiver fami frien	har Ily ids/	x .	If prime (choice	ry caregiver #18)		paid help: #28,38,48)	lf unpeld hel (#58,68	(p: ,78)	
		(eno)		4 10 10		aid Inpa Inpa	a fref id fe	essi imi jend	ional Y Js/	_ times	minutes	L L	ies minutes (write in)	L times _ m	inutes	
				2		npa	sion	la l		Intervier	ver: If mo add	re than bil insta	i one helper in inces of help	h each categor together.	χ.	
				(cir ap	ply)	all t	hat									
1		-	2	-	7	6	4	8	3 7	_ times _	minutes	- time	is _ minutes	_ times _ min	utes	
r.	Topical patch for pain management.	-	5	-	3	6	دن ج	SO	2 3	_ times _	minutes	_ time	s minutes	times _ min	lutes	
4	Injections (ex., pain meds/ insulin).	-	Я	-	2	r m	ی ب	0	7	- times _	minutes	_ time.	s minutes	_ times _ min	nutes	
с. О	Special IV Access care, (Hickman catheter, PICC line chest port, groshong, other).	-	Я	-	М	м Ф	2 +	9	2	times	minutes	t ti	t _ minutes	_ times _ min	lutes	
ю.	IV medications/fluids.	-	7	-	2	м М	· LO	0	7	_ times _	minutes	_ time	1 minutes .	_ times _ min	utes	
~	Infusion and pumps (for chemo, narcotics, or TPN).	-	7	-	2	۵ ۲	<u>م</u>	8	٢	_ times _	minutes	_ time:	, minutes	_ times _ min	utes	

, iCN

V/O PATIENT TELEPHONE ID/INT DATE/	NO B. If YES, who helps your C. In the past two weeks how many times and aproximately how long in minutes each time did it take to do this task? 1 You (primary caregiver) Pow long in minutes each time did it take to do this task? 1 You (primary caregiver) I = You (primary caregiver) 2 1 You (primary caregiver) If primary caregiver: 2 1 = You (primary caregiver) If primary caregiver: 2 = Paid friends/ (#58,68,78) 3 = Paid friends/ (#58,68,78) 0 others	2 1 2 3 4 5 6 7timesminutestimesminutestimesminutes	2 1 2 3 4 5 6 7timestimestimestimestimesminutes	2 1 2 3 4 5 6 7timesmInutestimestimesminutes	2 1 2 3 4 5 6 7timestimestimestimestimestimesminutes	2 1 2 3 4 5 6 7 times minutes times minutes times minutes
w/o P,	2 - N	7	7	7	7	7
VER	YES YES NO one	-	<u>5</u> . 1	-	-	-
INR/NCI WAVE II CAREGI	Does your require any of the following treatments or procedures?		Tube feedings: Includes g-tube inserted in gastric cavity: J-tube Inserted in the jejunum - small intestine; NG, nasogastric tube feeding	Mouth care (special rinses after chemo to treat/prevent mouth sores).	Skin care (special cleansing, lotions).	Care of ulcers/bedsores.

NINR/NCI WAVE II CAREG	siver	w/o Patien ⁻	тТ	ILEP	IOH	뿌				ID/INT DATE//	
A. Does your require any of the	YES	Q.	ë	ξ	ÈS,	ب ہ ≹	o he	alps your	C. In the past two weeks how man how long in minutes each time d	/ times and approximately id it take to do this task?	
rollowing treatments or procedures?	NO	- 6	- 0	×52	ou (iregi id fi	ver) ver)	λa γ		If primary caregiver: If paid help: (choice #18) (#28,38,48	lf unpeid help: (#58,68,78)	
	(circl one	96	е С	4 6	here i	rienc	ds/	Ī	times minutes times minut	ies times minutes	
			1 10 60	ເວີວິ	n pair Dair Dair	d far 1 frie	mily ende	, s/	(write in		
			7 =	855	hers npaix ofes	J sion	le		Interviewer: If more than one helpe add all instances of h	r in each category, iip together.	
			cire api	cle g	all th	lat					
	-	2	-	2		2	0	7.	_ times _ minutes times _ minute	istimesminutes	1 1
16. Constipation prevention: medications and/or enemas.	-	7	-	8	6 7	O	9	2	_ times _ minutes _ times _ minute	is times minutes	
17. Assistance because of incontinence of stool.	-	7	-	3	6 7	<u>د</u>	9	٢	_ times _ minutes times _ minute	is times minutes	
 Ostomy/colostomy care: bowel: external stool collection bag. 	-	7	-	8	4	a	S	٢	_ times _ minutes _ times _ minute	s _ times _ minutes	
19. Testing of urine or stool.		7		3	4	S	9	7	_ times _ minutes _ times _ minute	s times minutes	

(GO TO NEXT SECTION)

APPENDIX C

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MICHIGAN STATE UNIVERSIT

February 3, 1998

Barbara A. Given A230 Life Sciences TO:

97-679 COLORECTAL CANCER: AMOUNT OF CAREGIVER INVOLVEMENT FROM INTAKE TO 3 MONTHS AFTER DIAGNOSIS 01/09/98 1-8 IRB#: TITLE: RE: REVISION REQUESTED: CATEGORY: APPROVAL DATE: 1-E 10/06/97

The University Committee on Research Involving Human Subjects' (UCRIHS) review of this project is complete. I am pleased to advise that the right 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.

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. RENEWAL:

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/ 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. CHANGES :

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

lee ee Sincerely, Research Involving D Human Subjects ሄሌ (UCRIHS) David E. Wright, Ph.D. UCRIHS Chair Michigan State University 246 Administration Building East Lansing, Michigan DEW: bed 48824-1046

cc: Rose N. Birkmeier

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