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COLORECTAL CANCER: THE SYMPTOMS EXPERIENCED AND HOW THEY AFFECT A PATIENT'S FUNCTIONING ABILITY

By

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ABSTRACT

COLORECTAL CANCER: THE SYMPTOMS EXPERIENCED AND HOW THEY AFFECT A PATIENT'S FUNCTIONING ABILITY

By

Pamela Joy Chuey

Colorectal cancer is the third most common cancer occurring in men and women in the United States, specifically targeting the elderly. The incidence of this cancer will continue to rise as our elderly population increases. Despite the prevalence of this disease, little is known about the patients' experience who are undergoing treatment for colorectal cancer. This secondary analysis consisted of 117 patients, age 65 years and older, diagnosed with colorectal cancer who have reported their symptoms in type, number, and severity, after the initiation of their cancer treatment. The effect that the number and severity of symptoms have on the patient's functional ability (performing ADLs, IADLs, & mobility) were examined.

The findings from this study revealed that the combined effects of the number and severity of symptoms a patient experiences, the patient's age and current mobility, impact functional ability. The patient's current mobility was found to directly impact the patient's ability to perform ADLs and IADLs. Advanced practice nurses can use these findings to develop proactive plans of care targeted at timely symptom management and the prevention of the patient's functional decline.

This thesis is lovingly dedicated to my family
who have supported and encouraged me. To John,
whose love has carried me when school was a
bit much to bear. To Mea and Zack, whose laughter
and endless hugs continue to bring me joy.
To my extended family and friends who have helped
in many ways: watching my children, cooking meals,
cleaning house, providing encouraging phone
calls, pep talks, and a great supply of chocolate.

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INTRODUCTION

Colorectal cancer is the third most common cancer occurring in men and women in the United States and the second leading cause of cancer mortality (Sigurdson, 1995; Sinicrope & Sugarman, 1995). 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 eventually 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. The limited information available investigating colorectal cancer is well documented in terms of pathophysiology and is one of the most studied types of cancer in terms of both genetic and environmental risk factors (Slattery, Mori, Gao, Stat, & Kerber, 1995), however little has been written to describe the human experience of this type of cancer.

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, the prevalence of colorectal cancer among this population of both genders, and the mortality risk factors associated with colorectal cancer demonstrates the need to obtain greater knowledge of this 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. How does this particular type of cancer manifest itself within this population that is already vulnerable to concomitant disease? The information that encompasses the human experience of colorectal cancer is what is missing from the current body of knowledge. The purpose of this study is to describe the symptoms of colorectal cancer in patients 65 years of age and older, and how these symptoms affect their daily functional abilities.

Although the needs of a patient vary depending on the cancer site, the stage of the disease progression, the phase and aggressiveness of treatment options, and the treatment's resulting physical implications, during periods of acute exacerbation symptom management and control are of paramount importance. This avenue of inquiry can provide essential information that can assist health professionals to anticipate interventions that can help optimize patients' health and their ability to carry out daily activities. An understanding of the symptomatology of cancer and how it affects the patient's ability to continue to carry out their daily activities during their cancer treatment is paramount in providing comprehensive care for these patients, both in the hospital and at home.

Within the past few years, treatment regimens for people with cancer have shifted from in-hospital settings, being directed and supervised by health care professionals, to outpatient care, leaving day to day supervision of the patient to the primary family caregivers, and to the ill patient. The lack of information available regarding symptomatology of colorectal cancer and the resulting effect on the patient's ability to perform self care activities, leaves primary caregivers without the proper knowledge or preparation to care for their loved ones.

Currently, much of the care of cancer patients is taking place in the home, which demands knowledge of not only what to do to prevent and/or manage symptom experience, but also what needs to be reported to the health care provider. Hickey (1988) looked at the factual reporting of symptom complaints and found that older patients tend to underreport their symptoms when seeing their physicians. Given and Given (1994) discussed the burden placed on the patients and caregivers in monitoring symptoms and sequela, following treatment goals, transportation to appointments and administering medications. The concurrent presence of multiple symptoms such as fatigue, pain, and nausea can overwhelm patients and caregivers, causing feelings of helplessness and anxiety for all involved. These feelings are compounded as the patient and loved ones are cast into the role of health care provider in assessing patient complications or reactions to treatments as health care consumers take on the responsibility of monitoring symptoms or the side effects to treatment in the home setting.

This line of inquiry will carry needed knowledge to many areas of health care as the management of symptoms and assessment of needs after discharge is not limited to the nursing profession. A collaborative effort by a multidisciplinary team involving nurses, physicians, social workers, hospice care, and others, will benefit greatly from the outcome of this line of inquiry as a comprehensive proactive plan of care is developed for these cancer patients. Quality of life during disease exacerbation will be the optimal patient outcome that drives the following questions of inquiry for this research study:

1. What are the symptoms, in number and severity, experienced by colorectal cancer patients, age 65 years and older, at the time of treatment initiation?
2. How do the number and severity of symptoms experienced by colorectal cancer patients affect their functional abilities when analyzed by age and previous functioning ability?

Theoretical Framework

The number and severity of symptoms experienced during colorectal cancer and its treatment and the symptoms' effect on a patient's functional ability will have a direct impact on the patient's ability to maintain their own self-care. The concerns addressed in this study are clinically relevant to Dorothea Orem's Self-Care Deficit Theory of Nursing (S-CDTN). Orem's theory of nursing is a conceptual model comprised of three interrelated theories, the theory of nursing subsumes, the theory of self-care deficit which subsumes the theory of self-care (see Figure 1).

Orem's general theory focuses on the patient's ability to care for him/herself and the role of the nurse in assisting the patient in any identified areas of deficit in self-care. Orem's theory has proven to be versatile in nursing, providing a framework clinicians can use to develop specific plans of care by using one or all of the interrelated theories in the care of their patients. Orem's theory of nursing is relevant to all aspects of this line of inquiry, however the exploration of the relationship between patient symptoms and functional abilities is the realm of the self-care theory for this study.

The theory of self-care defines the concept of self-care as "the performance of practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and well-being" (Orem, 1991, p.117). The patient's ability or power to engage in self-care is defined as self-care agency, which develops from childhood, reaches maturity in adulthood, and declines with old age (Orem, 1991). In addressing self-care, Orem does

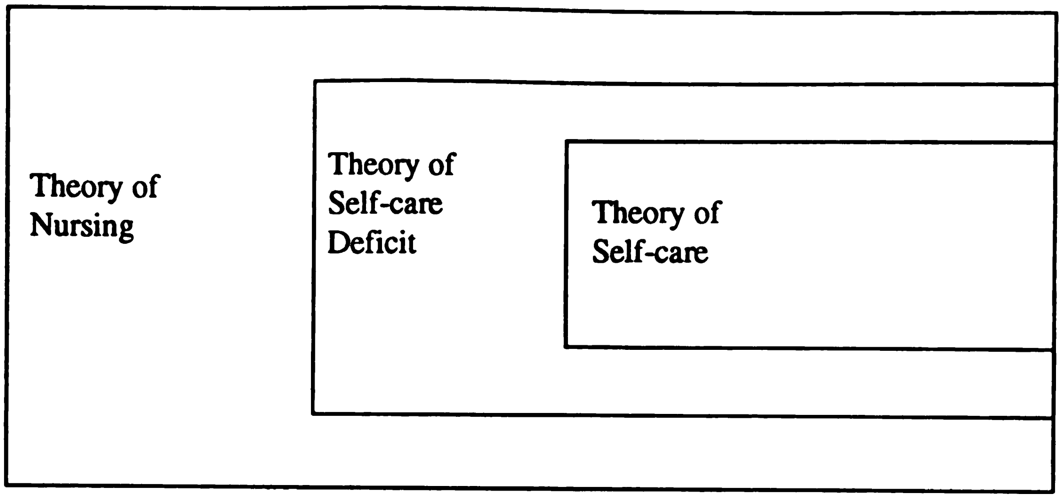


Figure 1. Constituent theories, the Self-Care Deficit Theory of Nursing.

adhere to the presupposition that self-care actions may vary by the cultural and social experiences of each individual. This acknowledges that self-care may not be initiated by even a healthy individual if learned helplessness is part of a person's cultural or personal characteristics, or an individual may insist on maintaining independence despite functional deficits for the same reasons. Noting the importance of assessing the client within the context of their own culture and health beliefs is a strength of this theory.

The relationship between experienced symptoms and the resulting effect on a patient's functional status can best be seen by examining the theory of self-care. Individuals have ideas of what health means, at least to them personally. Self-care is only one aspect of healthful living, but without continuous self-care that has a therapeutic quality, integrated human functioning will be disrupted. In the absence of illness, adults voluntarily care for themselves. However, "infants, children, the aged, the ill, and the disabled require complete care or assistance with self-care activities (Orem, 1991, p. 117). The population addressed in this study are all elderly patients, requiring regular assessment of their self-care abilities, even within the context of health maintenance. The symptoms experienced and potential functional alterations will have a direct impact on a patient's ability to maintain their self-care status. In the presence of a debilitating illness such as colorectal cancer, and the treatments that accompany this disease, Orem's theory of self-care provides a first step in the assessment process to determine when and how nursing care is needed.

The theory of self-care deficit evolved from the concept that individuals are affected from time to time by limitations that do not allow them to meet their self-care needs. These limitations in meeting self-care needs result in a self-care deficit. When a deficit is identified, through patient reports or the assessment process, nursing is required to assist the patient in achieving their self-care needs. The need for assistance may be long-term such as patient's with complete spinal cord injuries, or it may be for a short time, for example recovering from surgery or during periods of acute illness with adjunctive therapy in the treatment of cancer. Identification of self-care deficits is considered the core of Orem's general theory because it indicates that when an adult is incapable of, or limited in, the provision of continuous effective self-care, nursing is needed to assist the patient in their self-care demands. This assistance will continue until the patient has the ability and strength to utilize his/her own self-care agency and achieve independent self-care.

The theory of nursing systems describes all interactions taken by the nurse to assist the patient during their self-care deficit, and the actions taken to assist the patient in regaining their own self-care abilities. Orem further delineates self-care deficit as the need for nursing to physically assist in a wholly compensatory or partly compensatory capacity, depending on the extent of a patient's needs. Orem's theory identifies the supportive assistance provided through the personal relationship between the nurse and the patient/caregiver dyad and also through referrals to other members of the interdisciplinary team that may provide needed resources. In this supportive capacity, the nurse provides the education needed in anticipatory guidance regarding what to expect through the course of their cancer treatment and how to manage the effects of treatment at home. Supportive assistance is provided through the personal relationship between the nurse and the patient/caregiver dyad and also through referrals to other members of the interdisciplinary team that may provide needed resources. Orem's inclusion of the educational and supportive role of nurses as a component in nursing care emphasizes the importance of the nurse's role as a vehicle to empower patients and assist in promoting their ability to continue their own self-care. This illustrates the long-term assistance in providing care to patients with colorectal cancer and not just the self-limiting short-term physical care needed during acute exacerbation of symptoms and altered functioning.

Within this theory, maintenance or re-establishment of self-care is the goal of nursing interventions. Self-care can be identified as the pre-cancer baseline of the patients within this research population, or the optimal capacity that the patient is able to provide their own self-care, with the nurse or caregiver providing assistance as needed. The type, number, and severity of symptoms experienced, and the resulting impact on functional status will be the greatest determinant as to whether the patient will be able to maintain their pre-cancer baseline or if a self-care deficit results from the physical implications of colorectal cancer.

Nursing interventions occur throughout the diagnosis, treatment, and recovery phases of colorectal cancer. At diagnosis, education begins regarding the meaning of the diagnosis, treatment options, and anticipatory information on what to expect in the immediate weeks after diagnosis.

Nursing interventions continue during the initiation of treatment for colorectal cancer, as symptom distress begins. As patient and caregiver needs are continually assessed, anticipatory symptom management and education in the home management of symptoms occurs to assist the patient and caregiver to actively participate in the prevention of developing a self-care deficit.

If a self-care deficit develops as a result of symptom distress and functional disability, nursing interventions are focused on physically assisting patients in achieving their self-care needs and referring patients and caregivers to the needed resources to help obtain these goals once home from the hospital. Since the cancer does have periods of quiescence and exacerbation, this assistance may be short-term. However, the goal of nursing interventions within this framework is to assist the patient and caregiver to proactively decrease the number of symptoms, improve functional abilities, and achieve their optimal personal self-care status (see Figure 2).

The purpose of this study is to examine if the number and severity of symptoms impact a patient's functional ability. Examining these variables within Orem's theory of self-care, symptom count is defined as the number of symptoms a patient experiences after the initiation of cancer treatment. Symptom severity is defined as the patient's subjective rating as to the quality of their symptoms. A patient's functional ability will be defined as

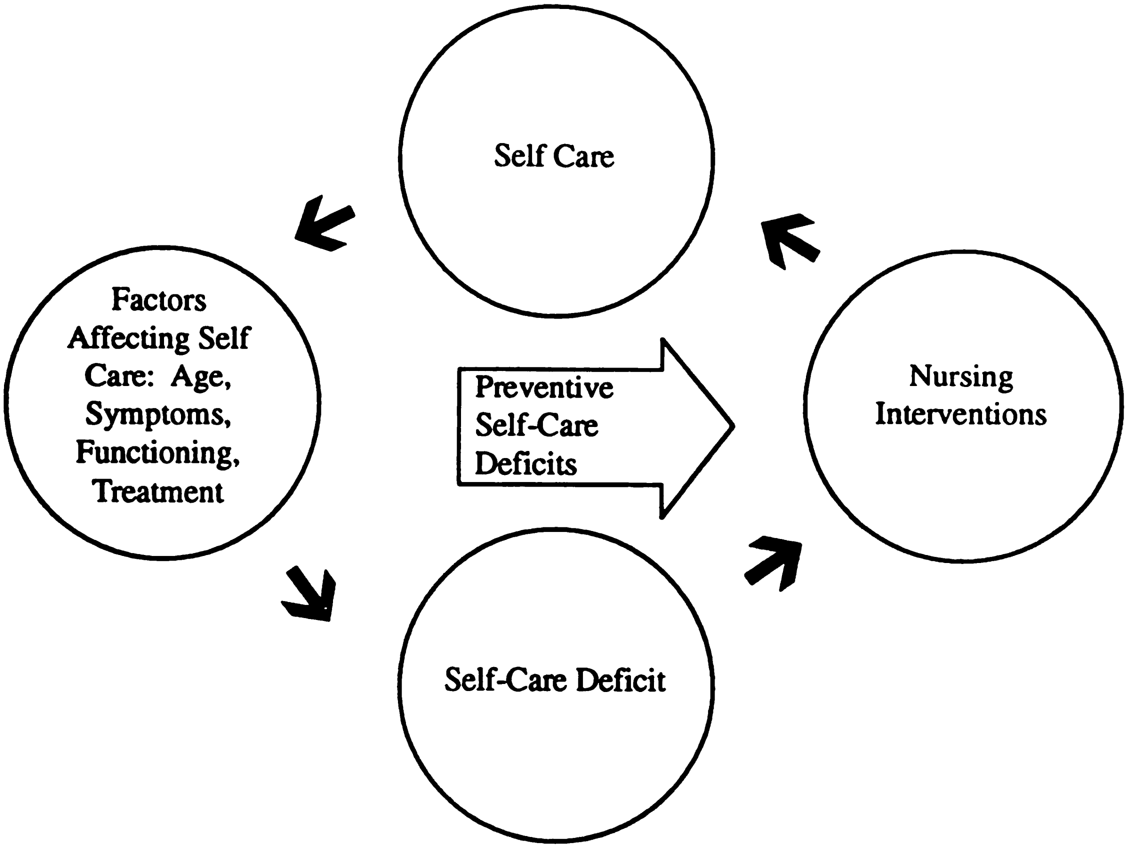


Figure 2. Expressing symptoms, functioning, and interventions within Orem's framework.

their ability to carry out activities of daily living (ADL), instrumental activities of daily living (IADL, and mobility (see Figure 3).

Review of Literature

The review of literature addressing symptomatology resulting from cancer and its treatment, and how it relates to a patient's functional ability will examine previous work completed in this field. It should be noted that the amount of empirical work available addressing this focus of study is limited. Analysis of the literature will be incorporated

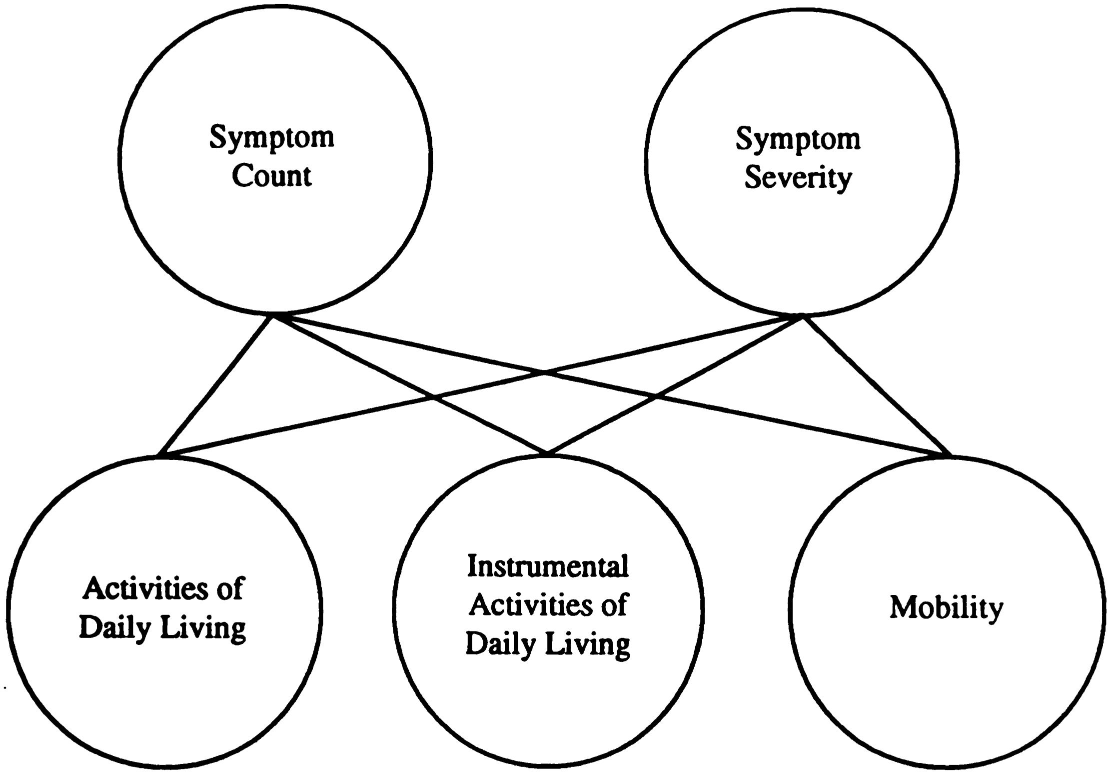


Figure 3: The relationship between symptom count and symptom severity on functional ability.

within this section of the review of literature, along with recommendations for the needed direction of future study.

Colorectal cancer is a disease that targets the elderly population. Research by Mor, Wilcox, Rakowski, and Hiris (1994), examined the functional abilities and the changes in these abilities that occur over time, and the changes that occur after a severe disability in people 55 years of age and older. Their study found that a return to independent functioning following a severe disability did occur for some of the elderly of all ages, however this was more rare among people 80 years old and older. The researchers' study showed that age influences the course of disability and the likelihood of death, even for people with similar baseline functioning (Mor et al., 1994). This finding supports research results from the Framington Disability Study (Jette & Branch, 1981), which found a consistent increase in physical disability with advancing age. These researchers pointed out, however, that the magnitude of disability is not as great as society believes. The results of both of these studies illustrates that age should be considered as a covariable in any study involving the elderly. Further data analysis by Mor and colleagues (1994) illustrates that an emergence of a new disability in previously independent elderly people leads to an increase in hospitalization. This finding indicates that it is fiscally beneficial to actively promote the recovery of a patient's functional status to decrease hospitalization costs.

Current literature indicates that the presenting symptoms of colorectal cancer vary depending on the tumor site. The most common symptoms alerting the clinician to a potential diagnosis of colorectal cancer include a change in bowel habits, paradoxical diarrhea, and changes in the stool (Steele, 1995). Other symptoms that patients experience may alert the clinician to the location of the tumor along the bowel or rectum. Weakness, secondary to anemia, is the symptom most commonly associated with a tumor of the right colon. Pain associated with a tumor in the right colon is ill defined, a tumor in the left colon presents pain that is often described as colicky, and a steady gnawing pain is indicative of a tumor in the rectum. Later stage tumors that have infiltrated into an around the lymphatic region present a feeling of an urgent need to defecate or urinate. Straining occurs with this effort, but evacuation remains unsuccessful.

Once a diagnosis of cancer has been confirmed, the patient may then choose a treatment intervention for their cancer which could include surgery, chemotherapy, radiation therapy, or any combination of these. The symptoms present which lead to the diagnosis of cancer may be exacerbated or compounded by other symptoms that may result from the chosen method of intervention.

Addressing symptoms experienced by patients undergoing chemotherapy encompasses the systemic side effects that may result from the treatment of the cancer, whereas symptoms resulting from radiation therapy or surgery will be more site specific depending on the anatomical area of cancer. Love, Leventhal, Easterling and Nerenz (1989) examined the effects of various forms of chemotherapy in the treatment of breast cancer or malignant melanoma. These researchers followed their participants through the first six cycles of chemotherapy, finding the side effects most frequently reported to be hair loss, nausea, and tiredness. These symptoms were reported by 80% of the patients at some time during their treatment intervention. In addition, vomiting, sleep disturbance, weight gain, mouth sores, and numbness and tingling were experienced by more than 40% of their sample.

Research by DeHaus, Van Knippenberg and Neijt (1990) examined two groups of patients: 1) female cancer patients, type of cancer unspecified, visiting an outpatient clinic for chemotherapy or follow-up; and 2) patients participating in a randomized trial comparing two chemotherapy regiments for advanced ovarian cancer, finding pain, fatigue, and gastrointestinal complaints to be significant complaints among their population. DeHaus and colleagues (1990) support the previous finding of Love and colleagues (1989), revealing the systematic nature of the symptoms experienced as a result of chemotherapy.

When surgery is used as a treatment option, the site specific symptoms experienced are distinctive in terms of nonstoma and stoma patients, and whether or not the sphincter remains intact after surgery. Patients with and without stomas were found to suffer from flatus, or gas in varying degrees (Sprangers, Taal, Aaronson & Velde, 1995). Stoma patients without intact sphincters report more problems with gas and urinary function, whereas patients with intact sphincters report more constipation.

Love and colleagues (1989) not only examined the symptoms experienced among their sample of patients with breast cancer or malignant melanoma, but also the frequency of symptom occurrence over a six month period of time. They found that the patient's symptoms would fluctuate in occurrence over the six month time frame of their study. The symptoms reported by patients in the study may occur, resolve, and reoccur within the course of their treatment, causing the patients to fluctuate between periods of acute distress and symptom quiescence.

The previous research work alerts all health professionals to the need for continual assessment of the patient's cancer experience and the uniqueness of treatment for each individual. These studies by Love and colleagues (1989), DeHaus and colleagues (1990), and Sprangers and colleagues (1995), explored the variety of symptoms that may occur resulting from the various treatment options in adjunctive therapies for cancer. Their work has provided valuable information directed toward increasing knowledge regarding the patient's personal experience of cancer and the need for professional attention to the development and utilization of preventative treatments or timely interventions in regard to symptom management.

The phenomenon of fluctuating symptoms which is described in the study by Love and colleagues (1989) can also be mirrored in the fluctuations seen in the limitation of physical functioning during treatment of cancer. Vinokur, Threatt, Vinokur-Kaplan and Satariano (1990) examined women with breast cancer and tracked their physical functioning over a ten month period of time. Their study showed that limitations in functioning do exist after treatment initiation, however these limitations improved over the course of the study. Results of their study also found that more extensive surgery is related to a more serious risk factor for reduced physical functioning and health among older patients, as compared to younger patients. Despite the good prognosis for marked improvement in physical functioning within the first year of diagnosis, these researchers found that full recovery in terms of mental health and well-being is a much more prolonged process. Vinokur and colleagues (1990) also identified that women over sixty years of age require greater assistance in overcoming difficulties in physical functioning, as compared to younger patients. Assuming generalizability to elderly patients with colorectal cancer, this research has identified the greater incidence of this population, aged 65 years and older, acquiring limitation in physical functioning as a result of cancer treatment, especially if extensive surgery is required.

The symptoms that patients experience do not occur as an isolated phenomenon. It can be hypothesized that the symptoms that patients experience will affect other areas of a patient's health. Analysis of the correlation between pain and limited functional ability was conducted by Portenoy, Miransky, Thaler, Hornung, Blanchi, Cigas-Kong, Feldhamer, Lewis, Matamoros, Sugar, Olivieri, Kemeny, and Foley (1992), looking specifically at patients with lung or colon cancer. Although there was no significant difference between these two populations with cancer, they found that over half of their patients perceived pain to interfere with general activities or work related activities to a moderate or great degree. Specifically, more than half of their patients reported a moderate or greater interference in sleep, mood, and enjoyment in life, and a smaller proportion stated that walking and social relations were at least moderately affected by pain.

Although this is the first study that identified colorectal patients as a large part of their sample, and isolated chemotherapy and its effects on patients' functional abilities, the time frame of the inquiry was a mere two weeks prior to the interview. However, generated information has been vital to this author's line of inquiry. It provides the stepping stone to an increased knowledge base of colorectal cancer specifically and has first addressed the relationship between symptoms and how they affect a patient's activities. This research also directs the need for future research to continue examining the influences of the symptoms of pain on functional abilities over a longer period of time.

The need to explore the correlation between the symptoms experienced and how they impact a patient's functional ability was first addressed by Daut and Cleeland (1982). These researchers interviewed patients with breast, colon, prostate, and various gynecological sites of cancer and found that the patient's perceived cause of pain, whether from the cancer, it's treatment, or from other unrelated factors, did influence the patient's perceived interference with activity and interference in their enjoyment in life. They also concluded that the perception of interference with activity and enjoyment of life was greatest when the patient's perceived their pain to be related to their cancer disease, as opposed to treatments or other factors. It is noted that pain is the only symptom analyzed, and evaluation of how it affects functioning is limited to the time at diagnosis and the month prior to the interview. This limits the ability to add to the knowledge of the long term effects of symptoms from cancer on the patients, however it did provide the beginning framework to examine this focus of study to a greater extent.

The need for continuing this line of inquiry to include more symptoms and examine the effects of these symptoms over a longer period of time was addressed in a longitudinal research study conducted by Kurtz, Given, Kurtz, and Given (1993). In this study, these researchers followed patients, 20 years of age and older, diagnosed with a solid tumor, for 6 months to determine the most commonly experienced symptoms they were experiencing and if the presence of symptoms could predict a loss in physical functioning. These researchers found the most frequently occurring symptoms in this population to be fatigue, pain, insomnia, nausea, and poor appetite, occurring throughout the six month study. Kurtz and colleagues found that the symptoms that patients experience was the most effective predictor of loss of physical functioning. Further analysis reveals which symptoms in particular were predictors for loss of physical functioning in each of their cancer groups: weight loss and pain were significant predictors for breast cancer, poor appetite was a significant predictor for lung and colorectal/gastrointestinal cancer, weight loss and insomnia were significant predictors for lymphoma, and pain was a significant predictor for other cancers (Kurtz et al., 1993). This research work was the first to explore multiple symptoms and their impact on functional ability, leading to an increased understanding of the sequela of cancer treatment.

Kurtz and colleagues (1994) reported on the same population after one year of participation in their study examining the symptomatology of cancer and its relationship to the effects of altering patients' functional abilities. These researchers found that most frequently occurring symptoms reported throughout their cancer treatment were pain, nausea poor appetite, and constipation. However, fatigue was the most prevalent symptom for all ages during the treatment of their cancer. Through this analysis, a positive correlation was found between a patient's symptoms and the patient's functional status, revealing that symptoms proved to be the only significant predictor of dependencies in activities of daily living (ADL). This study also illustrated that a patient's age is positively correlated with patient immobility. Results from the study showing the impact of age alone on a patient's health continued their previous work (Kurtz et al., 1993) examining the impact of age on physical ability throughout an entire year of cancer survival. The information generated from this study will assist health care providers to direct care to proactively prevent and/or treat the most frequently occurring symptoms experienced. This study further underlines the importance of managing the symptoms experienced during cancer treatment, as symptoms were shown to be a strong predictor of dependencies in ADLs.

Mor, Masterson-Allen, Houts and Siegel (1992) examined previous research work regarding symptoms and their effect on limitation of functioning, and included in their research design an evaluation of the patient's need for assistance and if those needs were being met. Mor and colleagues interviewed patients at baseline and once between three to six months after the initial contact for a follow-up interview. They found that a need for assistance with personal care and/or home health tasks rose from 7% at baseline to 16% at follow-up. Cumulatively, 60% of patients needed assistance with instrumental tasks, at baseline and/or follow-up. These researchers also found that selected medical and treatment variables were related to developing new needs. Those patients older than 65 years were 1.3 times more likely to have needs in personal assistance and patients with metastatic disease were significantly more likely to have acquired a new need in all areas. Having pain and nausea at the follow-up interview or reporting spending one or more days in bed in the two weeks before the follow-up interview indicated that a patient was at a higher risk for acquiring new assistance needs. The prevalence of unmet needs in instrumental tasks declined over the course of the study, with the cumulative probability of the unmet need at 18%. The prevalence of unmet needs in personal care was low at baseline (2%), however it did double over the course of the study and represents over one-third (37%) of those who reported needing help (Mor et al., 1992).

Research by Houts, Yasko, Harvey, Kahn, Hartz, Hermann, Schelzel and Bartholomew (1988), also examined the unmet needs of persons with cancer, focusing on the period of time during terminal care. These researchers found that needs related to 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. Results from their study showed significantly higher rates of unmet needs during the terminal period for activities of daily living, health care, problems with medical staff, and transportation.

The data generated from these two research studies by Mor and colleagues (1992) and Houts and colleagues (1988) indicate the necessity for investigating the many unmet needs of their cancer populations. Reported unmet needs are not only apparent for symptom management and functional maintenance, but the unmet needs in regards to interacting with health professionals and the apparent lack of advocacy occurring for these patients. These two studies have shown that any knowledge gained regarding the symptoms of cancer, their affects on functioning, and the needs of the elderly for assistance to carry out their functioning, is useless if it is not utilized in every day clinical practice. These researchers have identified that there are many needs of patients that are not being met and should alert the profession of nursing to the necessity of not only gaining the knowledge through empirical research, but also to utilize this information to proactively assist patients through their cancer experience.

As stated previously, research including patients with colorectal cancer is limited to a few studies (Kurtz et al., 1993; Kurtz et al., 1994, Love et al., 1989; Portenoy, 1992). Strengths of previous research on symptoms of cancer and functional abilities were evaluated including using standardized tests with known validity and reliability or the research involved a synthesis of previous works of the same focus of study. The use of standardized tests bring a greater validity and replicability to this line of inquiry. The natural progression of research inquiry was seen as Kurtz et al. (1993), Kurtz et al. (1994), and Love et al. (1989) addressed the multiple symptoms experienced by patients, as compared to Portenoy's (1992)focused analysis of pain. The need for longitudinal data was identified and accomplished in research conducted by Love et al. (1989) and Kurtz et al. (1994), with their studies following patients for a period of six months and one year respectively. Methodologically, these previous research designs are strong and have provided direction for the need for future studies to follow patients for a period of time of at least one year to assess the long term effects of symptoms and functioning, whether these variables continue, resolve, and/or have periods of exacerbation that continue for greater than six months.

This researcher's line of inquiry will examine the symptoms, in number and severity, experienced by patients with colorectal cancer and how these symptoms affect their functional ability. This analysis will be focused on the time after diagnosis, within six weeks after surgery or within ten days of beginning treatment. The reasons for this are three-fold: 1) As mentioned earlier, research specifically targeting colorectal cancer is limited. This author's research will replicate what has been done using only colorectal cancer patients; 2) Symptoms and their influence on physical functioning with colorectal cancer patients are greatest at the beginning of their diagnosis and treatment phase and during the terminal phase as well. Identification of symptoms is an essential piece of knowledge that will guide the nursing profession regarding the patient education that is needed and professional nursing interventions required for symptom management at home or in the hospital; and 3) Past research shows that symptoms of cancer are predictors of loss of functional abilities. Results from this study will increase the health care profession's knowledge regarding the symptoms experienced among colorectal cancer patients and assist in the guidance of preventive treatment needed for the most frequently occurring symptoms, and identify the patients who may require referrals to assistive agencies if a functional disability occurs as a result of overwhelming symptoms experienced.

Methods

To accomplish the goal of obtaining a greater understanding of the experience of colorectal cancer, it is necessary to utilize previous research works in the field which use colorectal cancer patients in their populations and continue to develop new research that examines the colorectal population specifically. The purpose of this study is to determine the symptoms, in type, number, and severity, experienced among patients with colorectal cancer and analyze how the number and severity of symptoms affect these patients' functional ability.

The participants for this study will be obtained from the original study's data base, consisting of 117 patients diagnosed with a new incidence of colorectal cancer. Eligibility criteria for this study include: 1) Participants were 65 years of age or older; 2) Participants must have an intervention for their cancer, either surgical, chemotherapy, radiation therapy, or any combination of these; 3) Participants must be English speaking; and 4) Participants had access to a phone. Patients with comorbid conditions were not excluded from the study. The particular state of the cancer or presence of metastases was not a criteria for eligibility or participation in the study.

The parent study utilized a nonprobability convenience sample. The selection of the 117 participants for this study occurred through convenience sampling from the parent study's data base of patients who fit the above criteria. Recruitment of cancer patients occurred during the patient's hospital stay or in the physician's offices during adjunctive therapy through six community-based cancer treatment centers located in lower Michigan.

The parent study utilizes a structured interview conducted by trained data collectors at the time of the participants' uptake into the study, followed by interviews at 6, 12, and 52 weeks. Each interview occurred over the phone, taking 45-60 minutes to complete. Information gathered for this researcher's study were only the portions of the interviews that are specific to this stated line of inquiry, which included interview items containing Likert scale questions addressing symptoms, activities of daily living, instrumental activities of daily living, and mobility.

Operational Definitions

Definitions for the variables addressed in this study will follow:

Age was defined as the number of chronological years that a person has lived.

Stages of cancer was defined as the classification of the tumor of the colon based on the size and extent of the primary tumor (T), nodal involvement (N), and distant metastasis (M). Staging of tumors ranged from 0 to IV. The TNM classification was defined as follows (Steele, 1995): Stage 0: carcinoma in situ (Tis, NO, MO); Stage I: tumor invades submucosa (T1, NO, MO) and tumor invading muscularis propria (T2, NO, MO); Stage II: tumor invades through muscularis propria into the subserosa, or into nonoperationalized pericolic or perirectal tissues (T3, NO, MO) and tumors that directly invade other organs or structures and/or perforates the visceral peritoneum (T4, NO, MO); Stage III: any degree of bowel wall invasion with regional node metastasis but without distant metastasis (any T, N1, MO); Stage IV: any degree of bowel wall invasion with or without regional lymph node metastasis but with evidence of distant metastasis (any T, any N, M1).

Treatment of cancer was defined as the method of intervention chosen for curative and/or palliative reasons. Treatments included any or all of the following: surgery, chemotherapy, or radiation therapy.

Symptom was defined as the somatic physical manifestations occurring at the time of cancer diagnosis and at any time after treatment initiation.

Symptom count was defined as the total number of symptoms that each patient experienced at the time of the interview.

Symptom severity was defined as the subjective rating of the quality of each symptom complaint.

Functional abilities was defined as the patient's physical ability to carry out every day tasks. A patient's functional ability was divided into three categories: 1) activities of daily living (ADL) which included dressing, eating, bathing, walking, toileting and transferring in and out of bed; 2) instrumental activities of daily living (IADL) which included a patient's ability to do laundry, shopping, housework, cooking and preparing meals, and independently drive him/herself; and 3) mobility which included a patient's ability to perform moderate to vigorous activities, lifting and carrying groceries, climbing one to several flights of stairs, bending/kneeling/stooping, walking one block to over a mile and bathing/dressing him/herself.

Instrumentation

Symptoms were defined as the subjective manifestations of cancer and its treatment as measured by the Given and Given Symptom Distress Scale (Given & Given, 1991). This symptom distress scale is comprised of a list of 37 symptoms such as nausea, poor appetite, fatigue, insomnia, and diarrhea. Each patient was presented with a symptom (such as nausea) and asked if he/she had experienced this symptom within the previous two weeks. If the patient answered "yes" to any symptom, they were then asked the severity of the symptom on a three-point scale ranging from mild to severe (1-3). The most severe rating was scored as three and the least severe scored as one. These questions explored the participant's symptoms that they had experienced in recent weeks and the quality of the symptoms complaints. The item-total correlations are high and the coefficient alphas are all above .90 (Given & Given, 1991).

Functional abilities measurement was accomplished through the use of the Medical Outcomes Studies (MOS) Physical Functioning Scale (Ware & Sherbourne, 1992). This tool measured how the patient's cancer, or the side effects of its treatment, may have interfered with any of the following: 1) activities of daily living: tasks such as eating, bathing, dressing, toileting, walking inside the house, and transferring in and out of bed; 2) instrumental activities of daily living: tasks such as laundry, cooking, housework, shopping and transportation; and 3) mobility: ability to lift or carry groceries, participate in moderate to vigorous activities, climb one to several flights of stairs, and walk one block to more than a mile.

Assessing activities of daily living and instrumental activities of daily living, using the MOS, was done using a five-point scale (1-5). The patient, or their caregiver, was asked about each ADL and IADL task and whether the patient is independent or needed assistance, such as supervision only, partial assistance, or total assistance. The items were then further evaluated as to if the assistance needed was due to cancer, other health problems, or if someone else has always performed this activity for them, which indicated that assistance needed may be related to health problems present before the diagnosis of cancer or related to established roles within the household. Further evaluation as to the potential etiology for the needed assistance helped to clarify the difference between ADL and IADL dependence ability and capability by capturing roles within the household as part of the measure. Mobility was assessed using a three-point scale, determining if patients felt that their health currently limited them in participating in any mobility tasks, with Likert scale answers ranging from "not limited at all" to "limits me a lot" (1-3). These questions determine the patient's perception regarding any limitations in mobility. These subscales of the MOS-36 have corrected item-total correlations above .60 to .62 respectively, and coefficient alpha of .85 and .84 respectively (Given & Given, 1991).

<u>Treatment of cancer</u> was defined as one or any combination of the following interventions for either curative or palliative measures: 1) surgery; 2) chemotherapy; 3) radiation therapy; and 4) any combination

of these therapies. This information is gathered from hospital records and verified by patients at the time of their signing consent to participate in the study.

Stages of cancer was defined as the cancer developmental state, such as a tumor confined to its place of origin or any stage extending to, and including, an advanced stage of tumor which has metastasized to various parts of the body. The stages of cancer were classified as I, II, III, or IV utilizing the TNM classification system (Steele, 1995).

Research Design

The original study collected data using a longitudinal descriptive-comparative research design. The Principal Investigators examined how age, comorbid conditions, the site and extent of prostate, breast, colorectal, or lung cancer, and the aggressiveness of treatment for the cancer, their impact on patient's functional and mental states, and the requirement of formal and informal care and its impact upon family caregivers. Data continues to be collected for the parent study. Each participant is being followed over a period of one year, the first interview occurring after the initial intervention for the patient's cancer, with follow-up interviews occurring at 6, 12 and 52 weeks (waves I, II, III, and IV, respectively). Drs. Barbara and C.W. Given are the Principal Investigators of the parent research study entitled the Family Home Care Study for Cancer--A Community-Based Model, grant #R01-NR01915, funded by the National

Institute for Nursing Research and the National Cancer Institute.

This researcher is doing a secondary analysis of the original data that was collected in the field, with the scope of inquiry limited to colorectal cancer patients only. Information collected at the participants' uptake into the study was the focus of interest for this researcher. This secondary analysis was a Level II nonexperimental cross sectional descriptive study design examining Wave I data, which is the first interview that occurred after the initial treatment intervention for the participant's cancer.

Data Analysis

The inquiry specified in Question #1 was analyzed using descriptive statistics. This accomplished the objective of reporting the symptoms, the type, number, and severity, experienced among patients with colorectal cancer. Further analysis of the data explored the total number of symptoms each patient experienced and the patient's perception of the severity of each of their symptoms.

Regression analysis is utilized for Question #2 to examine the causal relationship between the patient's number and severity of symptoms and the affect of these symptoms on a patient's functional ability after the initiation of treatment. This level of analysis was utilized to determine if there is a direct cause and effect relationship between the number and severity of symptoms and their impact on functional ability. The patient's age and current mobility were controlled for in the regression analysis of ADL and IADL due to literature stating that both age and mobility individually contribute to impact functioning (Mor et al., 1994; Vonkur et al., 1990) and to specifically isolate the impact of symptom count and severity on ADLs and IADLs. The patient's age was controlled in the regression analysis for mobility for the reason stated previously. Current mobility will not be controlled for in the analysis due to the perfect correlation between mobility and current mobility.

The total possible score for self-care and instrumental activities is forty-four, scoring for responses as to whether the patient is independent, needs some physical help, needs total physical help, or has never done the activity before (one, two, three, and four respectively). The total score is calculated as the sum of the scores for the questions in these two categories. The maximum score for self-care is 24, while the maximum score for IADLS is 20. Mobility has a total possible score of 27, which is the sum of the scores for the nine questions in this category. The possible scores are one, coded for "not limited at all", two for "limited a little", and three for "limited a lot".

Protection of Human Subjects

Research participants for this secondary analysis have already been recruited and interviewed for the parent study. When being approached for participation in the parent study, the patient/caregiver dyads were informed of the purpose and procedures of the study, such as the interview format and the number of interviews that were required for completion of one year of participation. If the dyads chose to participate, they signed an Institutional Review Board approved consent form.

There are no identified risks to the patient/caregiver dyads in the original study, which also 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 so the trained interviewers were able to call and arrange appointments to conduct the interviews for the data collection. All other documentation utilized for data analysis was restricted to the use of case numbers only, which were 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 had been completed.

For the purpose of this secondary analysis, this author has obtained approval for this study from the University Committee on Research Involving Human Subjects at Michigan State University.

Limitation of the Study Design

The sample size is small for the number of variables related to symptoms and functioning which prevents generalizability to all patients with colorectal cancer. A second limitation of this study was the requirement for participants to be English speaking and have access to a phone. This hinders an unbiased racial and ethnic mix within the study and potential socioeconomic considerations of the data from the population obtained. The absence of a mental cognition component in the questions may leave a reader to question the mental competence of this elderly population undergoing acute health changes. Cancer staging information from chart audits for each patient participating in this study was not available. This lack of information prevents further analysis corresponding symptom and functioning to any particular stage of cancer.

Another limitation of the study is the time required (45-60 minutes) for the interview to take place. The known health implications of undergoing chemotherapy and/or radiation therapy interventions for cancer permit only the healthiest of all cancer patients to participate in the study, as fatigue and symptoms addressed within the study might have prevented a patient's consent for participation. Instrumentation limitations included the overlapping of the evaluation of walking within both of the ADL and mobility scales. Measuring walking with two scales reduces the purity of the results.

RESULTS

Description of the Sample

Analysis of the data generated examined the type, number, and severity of symptoms experienced among colorectal cancer patients, and how the number and severity of these symptoms affected the patients' functional ability. The sample consisted of 117 patients with a new diagnosis of colorectal cancer who had recently begun treatment for their cancer. The sample was split almost evenly by gender, 56 males (47.9%) and 61 females (52.1%), with a mean age of 72.4 years (SD=6.1). The distribution of the staging of the cancer for these patients ranged from I-IV, showing 12.8% (n=15) diagnosed with Stage I, 19.7% (n=20) with Stage II, 17.1% (n=20) with Stage III, and 8.5% (n=10) with Stage IV (information was missing on 41.9%, n=52). Almost eighty-fiver percent (n=99) of the patients had undergone surgery for treatment of their cancer. Sixty-three percent (n=74) of the patients had begun adjunctive therapy (chemotherapy or radiation therapy), and twenty-seven percent (n=32) were scheduled to begin adjunctive therapy in the near future. According to Steele (1995), almost all patients will require surgery for their primary disease, at least to prevent obstruction or bleeding, staging of colorectal cancer guides the need for adjunctive treatment. Therefore, staging of the cancer was examined in an attempt to predict the sequela that occurs from each type of treatment option.

Ethnic distribution of the 117 patients included 101 Caucasians (86.3%), six African-American (5.1%), 1 Hispanic (.9%), and two identified as having other ethnic backgrounds. Fifty-two patients (44.4%) were married, five (4.3%) were single or have never been married, six (5.1%) were divorced or separated, and twenty-four (20.5%) were widowed. The level of education of the patients in this study was widely dispersed and included completion of grade school (6.8%, n=8), completion of some high school (12.8%, n=15), completion of high school (26.5%, n=31), completion of some college (26.5%, n=31), completion of college (12.8%, n=15), and completion of a graduate degree (6%, n=7). Two-thirds of the patients were retired (n=77) due to other reasons than their cancer, and 13.7% (n=16) identified themselves as homemakers. Eleven percent (n=12) of the patients continued to work either on a full-time or part-time basis. The combined household income for 14% (n=16) of the population was $19,000 or less. Close to nine percent (n=10) had a household income between $10,000 and $15,000, with nine percent of the population having a combined household income greater than $50,000. Seventeen percent of the sample did not wish to disclose this information.

The caregivers in this study consisted of 17 males (14.5%) and 47 females (40.2%), with missing information regarding gender on 45.3% (n=53) of the population at this time. The average age of a caregiver was 59.8 years (SD=12.9), with ages ranging from 31 to 70 years. Spouses consisted of 26.5% (n=31) of the caregivers in this sample, the patient's children and sons/daughters-in-law accounted for 7.7% (n=9) and .9% (n=1) of the caregivers, respectively. Other caregiver relationships included brother/sister of the patient (1.7%, n=2), grandson/daughter (.9%, n=1), niece/nephew (2.6%, n=3), or a friend/companion

(1.7%, n=2). The primary caregiver lived with the patient in almost 40% of the sample (n=46) and lived apart from the patient in 15% of the sample (n=17). The caregiver moved closer to, or in with the patient to assist with their cancer care in 2.6% of the population (n=3). Table 1 will visually display the sociodemographic distributions of this sample.

Answers to Research Questions

The first research question sought to determine the symptoms in type, number, and severity, experienced among colorectal cancer patients during the period of time after the initiation of treatment. Out of the 37 symptom complaints introduced to patients, only one was not responded to affirmatively by any of the patient population (the symptom of breast tenderness). The list of symptoms are presented in Table 2 to illustrate the most commonly occurring problems and what percent of the population experienced them. The ten most commonly experienced problems experienced by this sample of colorectal cancer patients in descending order of occurrence included waking up at night to urinate (66.7%), n=78), fatigue (66.7%, n=78), pain (42.7%, n=50), diarrhea (41.9%, n=49), weight loss (41.9%, n=49, dry mouth (40.2%, n=47), poor appetite (38.5%, n=45), weakness (38.6%, n=43), trouble sleeping (35.9%, n=42), and frequent urination (29.1%, n=34).

The total number of symptoms each patient experienced was summed and then analyzed to determine the frequency of

Table 1.

Sociodemographics of the Patient Population (N=117)

Sociodemographic Information	N	%
Patient Gender		
Male	56	47.9
Female	61	52.1
National Origin		
Caucasian	101	86.3
African-American	6	5.1
Hispanic	1	0.9
Other	2	1.7
Missing	7	6.0
Stage of Cancer		
I	15	12.8
II	6	5.1
III	1	0.9
IV	2	1.7
V	7	6.0
Treatment for Cancer		
Surgery	99	84.6
Chemotherapy or Radiation (begun treatment)	74	63.2
Chemotherapy or Radiation (scheduled to begin)	32	27.4
Caregiver Gender		
Male	17	14.5
Female	47	40.2
Missing Information	53	45.3
Caregiver Relationship to Patient		
Spouse	31	26.5
Daughter/Son	9	7.7
Daughter/Son-in-law	1	0.9
Sister/Brother	2	1.7
Granddaughter/Son	1	0.9
Niece/Nephew	3	2.6
Friend/Companion	2	1.7
Missing Information	68	58.1
Caregiver Lives with Patient		
Yes	46	39.3
No	17	14.5
Missing Information	54	46.1

Table 1 (cont.)

Sociodemographic Information	N	%
Combined Household Income		
$5,000-$9,999	16	13.7
$10,000-$14,999	10	8.5
$15,000-$24,999	27	23.1
$25,000-$34,999	26	22.2
$35,000->=$90,000	18	15.6
Missing Information	20	17.1

Table 2.

<u>The Type, Number, Percent, and SD of Symptoms Experienced Among Colorectal Cancer Patients in Descending Order of Occurrence with Corresponding Symptom Severity Mean and SD (N=117)</u>

	Symptoms			Severity	
Symptoms Experienced (N=117)	N	%	SD	Mean*	SD
Waking up at night to urinate	78	66.7	.45	1.3	.57
Fatigue	78	66.7	.45	1.6	.69
Pain	50	42.7	.50	2.0	.73
Diarrhea	49	41.9	.50	1.98	.83
Weight Loss	49	41.9	.50	1.6	.71
Dry Mouth	47	40.2	.50	1.5	.69
Poor Appetite	45	38.5	.50	1.8	.76
Weakness	43	36.8	.49	1.7	.73
Trouble Sleeping	42	35.9	.49	1.7	.77
Frequent Urination	34	29.1	.47	1.8	.74
Altered Taste	33	28.2	.46	1.5	.71
Itching	32	27.4	.46	1.4	.67
Urgent need to urinate	26	22.2	.43	1.4	.57
Lack of sexual interest	23	19.7	.41	2.0	.83
Nausea	22	18.8	.41	1.6	.73
Mood Changes	22	18.8	.40	1.4	.58
Sweats and night sweats	16	13.7	.36	1.7	.79
Cough	15	12.8	.35	1.4	.60
Difficulty concentrating	14	12.0	.34	1.3	.50
Mouth sores	14	12.0	.34	2.0	.88
Bleeding or bruising	13	11.1	.33	1.4	.65
Dizziness	13	11.1	.33	1.3	.48
Constipation	12	10.3	.31	1.8	.84
Difficulty breathing	10	8.5	.29	1.4	.52

Table 2 (cont.)

Symptoms Experienced (N=117)	Symptoms N	%	SD	Severity Mean*	SD
Coordination problems	10	8.5	.29	1.4	.70
Leg swelling	10	8.5	.34	1.3	.68
Vomiting	9	7.7	.28	1.8	.83
Hot flashes	9	7.7	.28	1.7	.71
Numbness/tingling/loss of feeling	8	6.8	.26	1.4	.52
Leaking urine	8	6.8	.26	1.6	.74
Fever	6	5.1	.23	1.5	.55
Dehydration	5	4.3	.21	2.4	.89
Difficulty swallowing	5	4.3	.21	1.8	.84
Limitation in arm movement	5	4.3	.25	1.6	.90
Vaginal dryness	3	2.6	.23	1.3	.58
Arm swelling	2	1.7	.16	1.5	.71

*Scale 1-3

how many patients within the sample experienced that same total symptom count. Through this analysis, it was found that the number of symptoms a patient experienced ranged from one (3.4% occurrence), to as many as 19 (1.7% occurrence) symptoms, with the sample population averaging 7.6 symptoms at the time after the initiation of treatment. Fifty-two percent of the patients (n=6) experienced seven symptoms or less. The number of symptoms occurring at the greatest frequency was six (12.8%), followed by nine and four symptoms (each occurring in 10.3% of the population). No one claimed fewer than one symptom (n=0).

The average severity of each symptom was tabulated to determine the extent of difficulty these patients were having with the symptoms they had experienced. The results showed that colorectal patients in this sample rated the severity of each symptom an average of 1.5 (on a scale of 1-3). Almost nineteen percent (n=22) of the average symptom severity scores were rated at 1, forty percent of the scores (n=47) were between 1.01 and 1.60, and thirty-six percent (n=42) were between 1.61 and 2.65 (see Table 3).

The second research question sought to determine how the number and severity of symptoms impacted a patient's functional ability. Table 4 illustrates the means and alphas of the ADL, IADL, and mobility scales of the items which comprise functional ability. The analysis of ADLs measured a patient's ability to dress, eat, bathe, walk, perform toileting, and transfer in and out of bed independently or if assistance was required for these tasks (1-5 point scale). The scale consisting of ADL activities (Alpha=.72) carried an item means of .08. The range of scores for ADLs included a minimum of 0.01 and maximum of 0.23. There was little variance of the means of all the tasks making up ADLs (dressing, eating, bathing, walking, toileting, and transferring in and out of bed). A maximum score of .23 indicates that all participants in this study remained independent in this functional activity.

The analysis of IADLs measured a patient's ability to provide self-transportation, do laundry, shop, housework, and cook and prepare meals (1-5 point scale). The scale consisting of IADL activities (Alpha .89) carried item means of .91. Item means of .91 indicated that some assistance

Table 3.

Distribution of Symptom Count and Symptom Severity Values

Overall Patient Symptom Count	Count (N=111) N	%	Average Symptom Severity	Severity* (N=111) N	%
1	4	3.4	1	22	18.8
2	6	5.1	1.01-1.14	4	3.4
3	5	4.3	1.15-1.20	5	4.3
4	12	10.3	1.21-1.27	6	5.1
5	11	9.4	1.28-1.33	9	7.7
6	15	12.8	1.34-1.40	5	4.3
7	8	6.8	1.41-1.50	10	8.5
8	6	5.1	1.51-1.60	8	6.8
9	12	10.3	1.61-1.71	8	6.8
10	7	6.0	1.72-1.77	5	4.3
11	8	6.8	1.78-1.83	3	2.6
12	6	5.1	1.84-1.89	5	4.3
13	3	2.9	1.90-1.95	2	1.7
14	1	0.9	1.96-2.00	6	5.1
16	3	2.6	2.01-2.09	2	1.7
17	1	0.9	2.10-2.14	3	2.6
18	1	0.9	2.15-2.29	4	3.4
19	2	1.7	2.30-2.63	4	3.4
Missing	6	5.1	Missing	6	5.1

Table 4.

Means, SD, and Alpha of Functional Ability Scales

	Mean	SD
Activities of Daily Living*		
Dressing	0.13	0.49
Eating	0.03	0.30
Bathing	0.23	0.67
Walking	0.01	0.10
Toileting	0.02	0.20
Transferring in and out of bed	0.03	0.30

ADL Reliability Alpha: .72
Item Mean Range: .01-.23

Table 4 (cont.)

	Mean	SD
Instrumental activities of daily living*		
Transportation	1.27	1.38
Laundry	0.86	1.24
Shopping	0.95	1.27
Housework	0.75	1.16
Cooking and preparing meals	0.70	1.14
Mobility**		
Moderate activities	1.14	0.87
Vigorous activities	1.54	0.72
Lifting and carrying groceries	0.91	0.90
Climbing several flights of stairs	0.82	0.85
Climbing one flight of stairs	0.52	0.79
Bending/kneeling/stooping	0.60	0.71
Walking one block	0.43	0.74
Walking several blocks	0.78	0.84
Walking more than a mile	1.02	0.88
Bathing/dressing yourself	0.31	0.53

Mobility Reliability: .89
Item Mean Range: .31-1.5

*Scale 1-5 (1=Independent, 2=Requires Supervision, 3=Some Physical Assistance Needed, 4=Total Physical Assistance Needed, 5=Never Performed Activity Before)
**Scale 1-3 (1=Independent/Not Limited at all, 2=Limited a Little, 3=Limited a Lot)

(minimum and maximum scores respectively). The item mean of cooking and preparing meals carries the scale's minimum mean of 0.70, while transportation provides the scale's maximum mean of 1.27, indicating that transportation was the area that patients required the most assistance.

The analysis of mobility measured a patient's ability to carry out moderate and vigorous activities, lift and carry groceries, climb one to several flights of stairs, bend/kneel/stoop, walk one to several blocks, walk more than a mile, and bathe and dress independently (scale of 1-3). The scale consisting of activities of mobility (Alpha .89) carried item means of .81. The range of scores for mobility were .31 (bathing and dressing independently) and 1.54 (performing vigorous activities), which carried the minimum and maximum scores respectively. Table 4 illustrates the means, standard deviations, and alphas of the reliability for the scales for ADLs, IADLs, and current mobility, which comprise a patient's functional ability.

Examination of the correlation between symptom count and symptom severity had revealed the inability to use these two variables within the same analysis due to their high correlation value of .92 (Sig. T of .000). Incorporating these variables that are so closely correlated would cloud any individual impact they may have on functional ability. It is for this reason that the variable of symptom count had been utilized and the average symptom severity variable had been utilized to encompass the extent of difficulty patients were having with their symptoms.

Through analysis of the scale comprising ADL activities, it was revealed that over two thirds of the sample were completely independent, with only 6 out of the 117 people requiring assistance in this area. Therefore logistic regression was utilized to analyze the impact symptom count and average symptom severity would have on the patient performing ADLs. In order to specifically target the impact of symptom count and average symptom severity on ADLs, covariables in the logistic regression that were controlled included age and the patient's current mobility, due to their individual impact on physical functioning (Mor et al., 1994; Vinokur et al., 1990). A patient may have limitations in mobility before their diagnosis of cancer which may be a result of a patient's decreased strength and cardiovascular endurance, sedentary lifestyle, or other comorbid conditions. Therefore, the patient's current mobility status has been controlled in this analysis to clearly isolate the impact of symptom count and symptom severity on the patient's ability to perform ADLs. The results of this analysis showed that the combined effects of the patient's age, current mobility status, symptom count, and average symptom severity had a significant impact on a patient's ability to perform ADLs (Sig F .0000). Evaluation of each of the variables revealed that the patient's age, symptom count, and average symptom severity (Sig T of .08, .72, and .64 respectively) did not have an independent impact on a patient's ability to perform ADLs, however the patient's current mobility was the greatest indicator in determining their need for assistance (Sig T .0003) after the initiation of treatment for their cancer.

To determine if symptom count and the average severity of symptoms impact a patient's ability to perform instrumental activities of daily living, a multiple regression analysis was utilized due to the greater variability within the IADL scale. The patient's age and current mobility have been controlled for in this analysis also to clearly isolate the impact of symptom count and severity on the patient's ability to perform IADLs. Moderate correlations between the independent variables (age, symptom count, average symptom severity, and current mobility) did not show colinearity in this analysis. Multiple regression data showed that the combined effects of age, symptom count, average symptom severity, and current mobility level did impact a patient's IADL activities (Sig F .0000). Determination of individual impact on IADLs was seen by examination of the Sig T of symptom count (.58), average symptom severity (.21), the patient's age (.31), and current mobility (.00). The results showed that again, a patient's mobility status was the greatest indicator in determining the need for assistance with instrument activities of daily living.

The examination of the effects of symptom count and average symptom severity on a patient's mobility was also done utilizing regression analysis. The patient's mobility was not controlled in this analysis due to the perfect correlation with the dependent variable, however age continued to be controlled. Results of the regression analysis showed that the combined effect of the patient's age, symptom count, and average symptom severity did impact the patient's mobility with a significant F of .0000. Determination of the individual impact of each of these variables was seen by examination of the Sig T of the patient's age (.0040), symptom count (.0569), and average symptom severity (.0072). The results showed that a patient's age and their average symptom severity individually impact a patient's ability to maintain their mobility status. Table 5 illustrates the regression analysis results of the impact of symptom number and average symptom severity on a patient's functional ability, which is comprised of ADLs, IADLs, and mobility.

Discussion of the Results with the Conceptual Framework

The results of this study supported Dorothea Orem's Self-Care Deficit conceptual model (Orem, 1991). The combined effects of a patient's age, current mobility, symptom count and average symptom severity have a significant impact on a patient's functional ability. The patient's age and the average symptom severity have a direct impact on a patient's mobility. A patient's mobility, in turn, directly impacts a patient's ability to perform ADLs and IADLs. Therefore, it can be concluded that the combined effects of a patient's age, their current mobility, and the number and severity of symptoms they are experiencing at the time after the initiation of treatment may result in a self-care deficit for the patient. Additionally, the nurse should be aware of the patient's age, mobility status, and the severity of their symptoms, as each will directly contribute the patient's functional ability. Prevention of developing a self-care deficit, or restoration to

Table 5.

Regression Analysis and Sig T of Symptom Count and Average Symptom Severity on ADLs, IADLs, and Mobility

	Significant T	
Activities of Daily Living		
Patient Age	0.0847	Combined Effects
Symptom Count	0.7248	Sig F
Average Symptom Severity	0.6423	0.0000*
Current Mobility	0.0003*	
Instrumental Activities of Daily Living		
Patient Age	0.3134	Combined Effects
Symptom Count	0.5758	Sig F
Average Symptom Severity	0.2127	0.0000*
Current Mobility	0.0000*	
Mobility		
Patient Age	0.004*	Combined Effects
Symptom Count	0.0569	Sig F
Average Symptom Severity	0.0072*	0.0000*

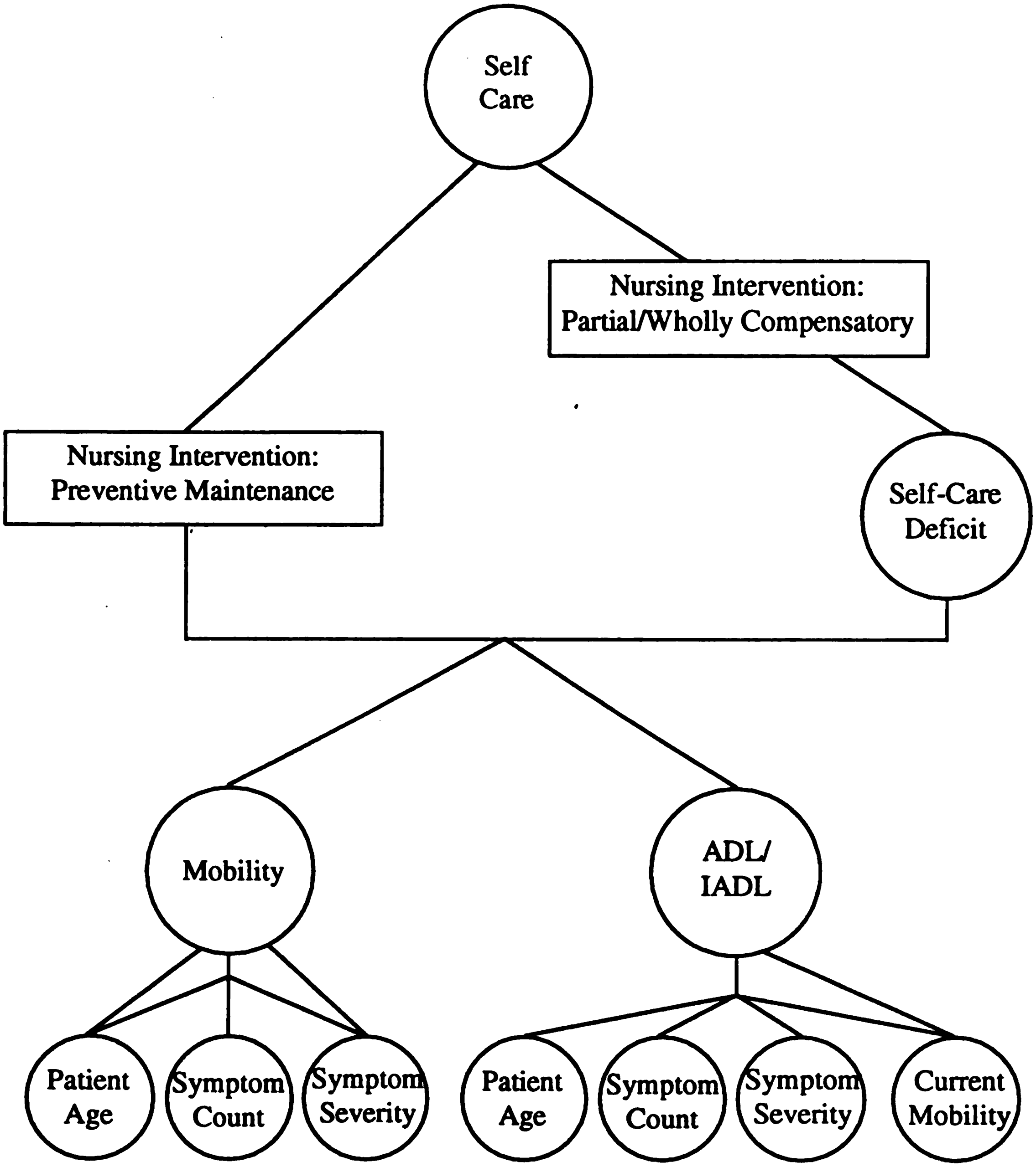
*Statistically Significant

independent self-care, will be dependent on the variables that can be modified, such as the severity of symptoms and the maintenance or improvement of the patient's current mobility status. Results from this study infer that minimizing or resolving the severity of symptoms will improve a patient's mobility, which will then improve a patient's ability to perform ADLs and IADLs, therefore returning to their self-care status (see Figure 4).

Discussion

Sample

In this retrospective descriptive study, a total of 117 patients diagnosed with colorectal cancer were surveyed to



<u>Figure 4</u>: Results of the Study Within Orem's Conceptual Framework

determine the type, number, and severity of symptoms they were experiencing after the initiation of treatment and how these symptom affected their ADLs, IADLs, and mobility. Out of 117 patients interviewed, 48% were men and 52% were women, with the average age of participants being 72.4 years (SD=6.1 years). Literature by the American Cancer Society (1996) states that colorectal cancer affects men and women in equal numbers and targets the elderly, with 62% of the cases diagnosed between the ages of 60 and 70 years, which is consistent with the demographics of this population except that diagnosis in this sample occurred at a slightly greater age (72.4 years). Eighty-six percent of the sample were Caucasian, 5% African-American, and 9% were other nationalities or had missing information. This is also consistent with the previous research studies identified in this paper, which contain largely Caucasian dominated samples, with little minority representation.

Eighty-five percent of the patients in the sample had undergone surgery for their cancer. This demographic characteristic is supported by Steele (1995) which states that surgery is the primary therapy for colorectal cancer with almost all patients undergoing surgery, at least to prevent obstruction or bleeding.

The caregivers in this study consisted of 40% females (n=47) and 15% males (n=17), averaging 59.8 years in age. Literature by Given and Given (1995) and Olson (1989) support this information with their findings that caregivers for patients with cancer are often women over 55 years of age. Further evaluation revealed that 27% of the caregivers in this sample were spouses (n=31), the gender of the spouses being split almost equally (20% male and 21% female). This also supports literature of the American Cancer Society (1996), referring back to the statement that colorectal cancer affects men and women equally, which then leaves their counterpart spouse in the caregiving role.

Almost 40% of the caregivers lived with the patients in this study. If a spouse was not present or unable to act as caregiver, older cancer patients were more likely to be cared for by their adult children. This is supported by the demographics in this study which showed that a daughter or son acting as caregiver accounted for the second largest percentage (7.7%) of caregivers of the data available.. In these situations, the adult children may have changed their living arrangements temporarily (by moving closer to our in with the patient) or visited the patent in their home more frequently to assist in their cancer care, however living together was not usually a permanent arrangement. This trend was seen in 2.6% of the sample, who moved from their previous living arrangements to assist with the care of their loved one.

The combined household income for almost 14% (n=16) of the patients was $9,999 or less, putting them at or near the poverty level, which has been determined to be $9,930 by the United States Census (1997). The combined household income for close to nine percent (n=10) of this population was between $10,000 and $15,000, with nine patients making more than $50,000. This illustrates that many patients were living on a moderate to low income and can still expect to receive medical bills to pay for the patient's cancer care. Many of the patients were retired and therefore living on a fixed income that had been established years prior to their diagnosis of cancer. The financial status of a patient becomes important if a patient lacks health insurance, if health care costs exceed the financial resources of the patient, or if assistance is required in the home. Fiscal limitations may force a patient to discontinue needed medical treatments or may limit their ability to continue with needed follow-up appointments. Financial assistance may be available to the very low income patients. However, those patients who make too much money to be considered very low income, yet are still struggling to make ends meet, are left to find assistance from other resources, such as from their family or church. The percentage of patients on Medicaid, Medicare, or Medigap has not been examined within this study and should be included in future research work.

The demographic characteristics of the sample were largely consistent with the literature. The patents were split almost equally in percentage of males and females, as were their counterpart spouse caregivers. The age at time of diagnosis is slightly higher than the literature reports, however the difference is small enough to be considered a normal standard deviation. The female caregiver, aged 55 years and older, follows typical demographic characteristics established by the literature, with adult children likely to take over the caregiving role if a spouse is not present or able to participate in this capacity.

Symptoms Experienced

Among this sample, patients identified a total of 36 different symptom complaints. No one experienced fewer than one symptom. The ten most frequently occurring problems at the period of time following the initiation of treatment for their cancer were waking up at night to urinate, fatigue, pain, diarrhea, weight loss, dry mouth, poor appetite, weakness, trouble sleeping, and frequent urination. The large majority (85%) of these patients had undergone surgery as treatment for their cancer, which may account for the high incidence of fatigue, pain, diarrhea, urinary problems, and trouble sleeping, which were symptoms typically found in patients recovering from surgery. Two thirds of the population experienced waking up at night to urinate and/or fatigue. Forty percent experienced pain, diarrhea, weight loss, and dry mouth. Poor appetite, weakness, and trouble sleeping were experienced by 36-39% of the sample, and frequent urination was experienced by almost thirty percent of the sample. These findings are supported by research in the field, when patient samples included colorectal patients, examining cancer and its symptoms (Steele, 1995; Kurtz et al., 1993; Kurtz et al., 1994; Mor et al., 1994).

The presence of urinary problems was the most common complaint and may result from various etiologies. Urinary problems may have been present before the diagnosis of cancer, and may have continued or gotten worse. Prescribed medications may cause or worsen urinary problems, or these problems may have occurred as a result of the proximity of the bladder to the colon for patients who have undergone colon surgery and/or radiation treatment. 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). In this study, fatigue and pain were the second and third symptoms experienced among this sample, with 67% and 43% of the patients complaining of these difficulties respectively. Within this sample, 42% of the patients had experienced diarrhea. The symptom of 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 diagnostic nature of diarrhea and the interview occurring so close to cancer diagnosis, this symptom can be expected to be present in a large percentage of the population.

The wide variety of symptom complaints (36 in number) voiced by this sample may be attributed to a patient's chosen method of treatment, the closeness of the interview following surgery, or may be related to a patient's preexisting medical condition. Research by Sprangers et al. (1995) found that diarrhea, urinary problems (with increased incidence in patients receiving stomas), and disturbed sleep were 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 of this inquiry, showing that at least 29% to as many as 67% of the population experienced at least one of these symptoms (diarrhea, urinary problems, and/or disturbed sleep) at the time after the initiation of treatment. This finding is not surprising due to the large percentage of patients undergoing surgery as treatment for their primary cancer and the proximity of the interview to the surgery date. It has been found that at least 29% to as many as 67% of the population experienced at least one of these symptoms at the time after the initiation of treatment.

Symptom complaints that may be related to the method of intervention of chemotherapy included nausea, vomiting, altered taste, dizziness, and fatigue. The nature of this type of treatment causes systemic symptomatology, which might have accounted for the wide variety of symptom complaints. These systemic symptoms may have occurred in addition to, or may exacerbate, the more site specific symptoms mentioned earlier related to surgery (diarrhea, urinary problems or disturbed sleep). Previous research supports these findings of the systemic nature of chemotherapy, with its accompanying diverse symptomatology, in their examination of various forms of this type of treatment. The symptoms most frequently reported in these studies included hair loss, nausea, tiredness, and gastrointestinal complaints (Love et al., 1989; DeHaus et al., 1990). Research by Love et al. (1989) followed symptom complaints throughout the patient's first six cycles of chemotherapy, which accounted for the complaint of hair loss, which occurs in the later stages of treatment and not at treatment initiation. Of the symptoms most frequently reported in previous research work involving chemotherapy, in this study fatigue is by far the symptom that affected the largest percentage of patients (67%). However this may have been a result of the commonality of this symptom complaint for all of the cancer interventions examined in this study (surgery, chemotherapy and radiation treatments). The dispersion of other symptoms found by Love and colleagues (1989) within this sample of colorectal cancer patients, included altered taste, experienced by 28% of the patients, followed by nausea (19%), dizziness (11%), and vomiting (8%). Inclusion of all treatment interventions (surgery, chemotherapy, and radiation therapy) may have accounted for the dispersion of the symptoms in this sample, as compared to the work by Love and colleagues (1989).

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.

Symptoms such as difficulty swallowing, arm swelling, coordination problems, or limitations in a patient's arm movement each occurred in less than 10% of the sample. These are vague complaints that appear to have little to no correlations with a patient's cancer diagnosis or with any kind of treatment. It is with this in mind that a patient's health status prior to the diagnosis of cancer and the possibility that the treatment for cancer may exacerbate pre-existing conditions. Previous surgeries may render a patient with chronic limitation in movement. Comorbid conditions such as diabetes or hypertension may result in numbness or tingling in the extremities or occasional dizziness. Seasonal changes in the weather may cause dry mouth or sweats. Patients may have lived with the above conditions for a number of years before their diagnosis of cancer, however they reported these previous conditions have been exacerbated by their chose method of treatment. Despite the interview questions asking the patients to attribute symptom complaints to their cancer, some complaints may cause confusion for the patients as to the etiology of specific symptoms (i.e., sweats or nausea may be related to the flu, however, it is up to the patient to diagnose if these symptoms are a result of a compromised immune system secondary to cancer treatment or just an isolated occurrence of gastroenteritis). Therefore all symptoms may not be directly related to a diagnosis of colorectal cancer or its treatment, but may be compounded by diagnosis and/or cancer treatment.

Previous research by Love et al. (1989) described the fluctuations that occur in symptom experience over the course of time as a result of chemotherapy treatments. This is beyond the scope of this study due to the interview occurring at only one time during the patient's cancer treatment regimen. It can be hypothesized, however, that since this analysis occurs after treatment intervention, symptom occurrence will decrease over time for patients who have undergone only a surgical intervention. A gradual return to baseline health and diminishing symptoms is normally seen in patients as they recuperate in the weeks following surgery. Utilizing the findings of Love et al. (1989), and assuming generalizability to the patients in this sample who utilize chemotherapy or radiation therapy, it can be hypothesized that the number and severity of symptoms will fluctuate over the course of the patient's treatment. This will be keenly evident in patients undergoing chemotherapy and radiation therapy, with the number and severity of symptoms peaking and diminishing, the symptom exacerbation coinciding with their adjunctive treatment and resolving during the period of time between their treatment cycles.

This study has shown that a patient experienced an average of seven symptoms after the initiation of treatment. No one reported fewer than one symptom. Although the research works mentioned previously explored the most frequently occurring symptoms in their populations, the average number of symptoms experienced has not been reported. Therefore, comparatively, it is not possible to determine if this is a larger number of symptoms for this particular cancer population. However, it can be postulated that the reported seven symptoms is possibly an underestimation, as research by Hickey (1988) has found that the elderly tend to underreport their symptoms. Therefore, the age of this population indicates that the average number of symptoms experienced may be higher than the results of this study have indicated.

Whether a patient's symptoms were a result of the cancer itself, from pre-existing conditions that had been exacerbated, or the treatment of cancer, the difficulty that a patient experienced was reflected in the severity score for each symptom. The average severity of symptom complaints was 1.52, with a minimum severity complaint of 1.0 and a maximum complaint ranked at 2.63 on a 1-3 point scale. Therefore, for each symptom complaint, a patient perceived as being the most severe (scored at 2.4), followed by pain, diarrhea, lack of sexual interest, and mouth sores, which were scored at 2.0 (on a scale of 1-3). The ten most frequently occurring symptoms and their corresponding severity scores, on a scale of 1-3, included waking up at night to urinate (1.3), fatigue (1.6), pain (2.0), diarrhea (1.98), weight loss (1.6), dry mouth (1.5), poor appetite (1.8), weakness (1.7), trouble sleeping (1.7), and frequent urination (1.5). It can be assumed that having seven symptoms rated at a mild to moderate degree of severity will have a significant impact on a patient's life.

Symptom Count, Symptom Severity, and Functional Ability

The determination of the impact of symptom count and symptom severity on functional ability was accomplished by examining ADLs, IADLs, and mobility separately. To isolate the specific impact of symptom count and average symptom severity on ADLs and IADLs, age and patient's current mobility were controlled. Previous research (Mor et al., 1994; Kurtz et al., 1994) indicated the need to control for age, as this variable does independently influence the course of disability. Including age as a covariable eliminated the bias that may occur with this elderly population and assisted in presenting clear findings regarding the specific impact of symptom count and average symptom severity on functional ability. A patient's current mobility status would also affect their ability to perform ADLs and IADLs. An impaired ability to climb stairs (a mobility task) may limit a patient's independence in washing if the bathroom is upstairs, or doing laundry, if these facilities are in the basement. Therefore, mobility was controlled to avoid any bias in this analysis regarding if assistance in ADLs and IADLs was due to the patient's present mobility status as opposed to the impact of symptom count and severity. Again, this was done to specifically isolate the impact of only symptom count and average symptom severity on ADLs and IADLs, controlling for all other factors that may have also affected functional ability.

Results were similar for both ADLs and IADLs, showing that the combined effects of symptom count, average symptom severity, the patient's age and the patient's current mobility did collectively impact a patient's ability to perform their activities of daily living and their instrumental activities of daily living, all with Sig F .0000. However, independently, neither symptom count nor average symptom severity directly impacted ADLs or IADLs. The variable that did independently influence the patient's need for assistance in ADLs and IADLs was the patient's mobility status. This result is interesting in that previous research (Portenoy et al., 1992; Daut & Cleeland, 1982) has clearly correlated symptoms with a loss of physical functioning. This may be explained by methodology, in that these prior studies interviewed patients at different times than this study, including the period of time well into their treatments.

The results from this study differ from previous work possibly as a result of different measures and analysis techniques. ADLs (dressing, eating, bathing, walking, toileting, and transferring in and out of bed) and IADLs (transportation, laundry, shopping, housework, and cooking and preparing meals) are comprised of concrete tasks that make up these two functional abilities. This list of specific tasks directed the patient to identify specific areas of needed assistance within each category of ADLs and IADLs. Portenoy and colleagues (1992) examined only one symptom (pain) and utilized categorical scales to explore the interference of pain with general activity, walking, mood, sleep, social relations, work, and enjoyment of life. These categories of various activities were broad for patient interpretation, having the patient assess an overall interference in life. The difference between identifying specific tasks within the ADL and IADL categories and inquiring as to whether assistance has been needed to accomplish these tasks, provides a greater clarity as to the extent of impairment in these areas. Therefore, the results of the analysis of the impact of symptom count and average symptom severity on ADLs and IADLs was more specific to the tasks involved in a patient's functional ability.

Another area of difference of this study from previous work was the decision to control for the patient's current mobility. The physical functioning of a patient may be impaired before the diagnosis of cancer as a result of comorbid conditions such as arthritis, heart disease, or Parkinson's disease. The average age of the patients within this study (72.4 years) lends to the assumption that the large majority of participants will have at least one comorbid condition that will have an impact on their cancer experience and convalescence. Although these conditions may have been present before the diagnosis of cancer and the patients were asked during the interview if the tasks of mobility were limited as a result of their cancer diagnosis or treatment, controlling for current mobility will eliminate any bias that may occur from the patient misunderstanding the specificity of the question related to the affects of cancer on mobility. For purity of results, controlling for a patient's current mobility has been done to pull out the specific impact the number of symptoms and their average severity has on a patient's functional abilities.

A limitation of these analyses is that the surgical impact on mobility has not been examined. The recovery process of surgical patients in itself involves limiting a patient's mobility. Immediately after surgery, the patent is restricted to short walks in their room and/or hall. The mobility of these patients will gradually increase as their strength returns following surgery and as prescribed limitations (such as lifting heavy objects) are removed during follow-up visits. The results of this analysis showed that mobility is the greatest indicator of the need for assistance with ADLs and IADLs, however, the specific cause of lack of mobility have not been addressed. Considering that eighty-five percent of the patients had undergone surgery for their cancer, the patient's previous functioning ability (prior to the diagnosis of cancer) should be controlled in future research, with the assumption that the need for assistance with functional abilities before the cancer diagnosis does not reflect the effects of cancer. Therefore, controlling for previous functional abilities should capture limitation in functioning that may result from surgical interventions. Future research should examine the etiologies of mobility through statistical analysis to assist in further predicting the patients who will require assistance with their ADLs and IADLs.

Mobility, as a component of functional ability, had been analyzed to determine the impact that has been exerted by the number of symptoms and average severity of symptoms a patient might have. The results showed that both the patient's age and the severity of symptoms did impact a patient's mobility status. Research by Kurtz et al. (1994) supported these results with their findings that loss of physical functioning was associated primarily with symptoms. This study separated the number of symptoms from their severity to determine which would have the greatest impact. Results from this study leads the reader to assume that a patient may have as many as 13 symptoms, but if he/she perceives them to be limited in severity, their mobility will not likely be disrupted. However, a patient may have only one symptom (fatigue or diarrhea, for example), but if it is considered to be severe in nature, their mobility becomes impaired. Fatigue may result in limitation in a patient's mobility due to the lack of energy to participate in their previous regimen of walking or golfing. Severe diarrhea may hinder mobility by leaving the patient with a feeling of their inability to leave the house for fear of not being able to find a rest room when needed. Immediately post-op, a patient's mobility is restricted to short walks to the bathroom, however that continues for only 24-36 hours. Recovery from that time on may limit mobility due to related symptoms such as pain.

Through these analyses, it was determined that the combined effects of a patient's age, current mobility, symptom count, and their average symptom severity had an impact in a patient's ADLs and IADLs. Symptom severity and age directly impacted a patient's mobility, and a patient's mobility directly impacted the need for assistance with ADLs and IADLs. Therefore, the severity of a symptom, such as pain, directly impacted the patient's mobility, which then would be a predictor of potential needed assistance with activities of daily living and instrumental activities of daily living.

This study showed that this sample of colorectal cancer patients experienced an average of seven symptoms at the time after the initiation of treatment, with a perceived average severity of 1.52 (on a scale of 1-3). In all analyses, the combined effects of the patient's age, current mobility, symptom count, and average symptom severity had a significant effect on the patient's functional ability, which included ADLs, IADLs, and mobility. The number and severity of symptoms a patient experienced did not directly impact a patient's ability to perform activities of daily living or instrumental activities of daily living when the patients' age and current mobility was controlled for. Results did show that the patient's age and severity of symptoms did directly impact the patient's mobility, and the patient's current mobility did have a direct cause-and-effect relationship on a patient's ability to perform ADLs and IADLs.

Implications for Advanced Practice Nursing

Colorectal cancer is the third most common cancer and the second leading cause of cancer mortality, occurring in men and women equally and targeting the elderly. With our elderly population increasing, the prevalence of this cancer will continue to rise. The movement of cancer treatments from in-hospital to outpatient settings leaves the patient and caregiver to manage the day-to-day symptoms and treatment goals of their cancer, such as transportation to appointments, following treatment plans, and administering of medications. 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 collaborative expertise with all involved health care professionals, and the capacity for APNs to advocate for patients and their family during their cancer experience.

A comprehensive assessment of the patient and caregiver's knowledge, expectations, and needs is an essential first step in assisting the family during their cancer experience. Assessment of the patient/caregiver's knowledge and expectations should include an evaluation of the 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 (APN).

The advanced practice nurse must use her clinical skills to thoroughly assess the patient and/or caregiver's needs. This assessment will be essential in developing the plan of care with the patient and caregiver, and should include physical and psychosocial needs. This assessment should be based on past medical history, cancer stage and chosen treatment, consideration of resources in the home, and any other verbalized needs.

This study has identified that a patient experiences an average of seven symptoms at the time of treatment initiation, rating them at a mild to moderate degree of severity. 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 or alleviating factors, the current home management treatment for that symptom, and if the symptom was present before the diagnosis of cancer. The identification of symptoms can be aided by considering the site of the tumor, stage of cancer, and method of treatment. Swift and thorough determination of the patient's symptom complaints may be achieved through the use of an assessment tool that could consist of presenting numerous symptoms in list-life fashion, and asking the patient to mark each symptom he/she has been experiencing. This assessment tool could also contain a rating scale to determine the patient's perception of the severity of each symptom complaint.

After the patient's symptom assessment is completed, the APN can then assist the patient in symptom control through timely interventions and instruction on home management to diminish the severity of these symptoms and therefore improve clinical outcomes. Improvement of clinical outcomes can be measured by a reduction in the severity or number of symptom complaints as reported on the symptom assessment tool with each visit. Reduction of the symptoms, in severity, will diminish the potential of a patient developing a functional disability in ADLs, IADLs, and/or mobility, therefore also improving clinical outcomes.

Through the results of this study it can be assumed that a large majority of patients with colorectal cancer will experience nocturia or fatigue or both. The APN can educate the family on restricting fluids or eliminating fluids two hours before bedtime to decrease the frequency a patient has to get up during the night to urinate. Examining the medication schedule of the patient might reveal the necessity to educate the patient on the timing of their medication and suggest taking their prescribed diuretic at 5:00 p.m. instead of 7:00 p.m., which would have the peak action of this medication kick in during wakeful hours, thus decreasing or eliminating getting up at night.

Fatigue can be managed at home with the help of the APN by initially providing 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. Encouraging family and friends to assist with activities such as housework, shopping, and cooking/preparing meals frees the patient from daily activities and will promote rest time. It will also be important for the APN to discuss with the patient and 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 fatigue and the multiple appointments involved in cancer treatments, 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.

Treatment of other symptoms experienced by patients should include a thorough assessment by the APN and collaboration with the family and other health disciplines as necessary. The APN can manage nausea through education on the preparation of bland diets, encouraging small frequent meals, and/or prescribing antiemetics and educating the family on timely administration of the medication, before the nausea becomes too severe or before their adjunctive therapy to prevent the nausea from occurring. Most symptoms experienced can be managed by the APN through education of the patient and family, anticipatory guidance to prevent exacerbation of symptoms, timely interventions to diminish the severity of symptoms, and collaboration with the family to determine effectiveness of any intervention and the family's ability to carry out treatment plans at home.

The advanced nurse practitioner must not only be alert to the many symptoms that patients are experiencing, the APN must also be alert to the implications of the severity of these symptoms. The most important study finding is that symptom severity directly impacts a patient's mobility. Therefore, it is imperative for APNs to address timely interventions to minimize symptom severity to prevent mobility impairment. Limitations in mobility may prevent or hinder the patient from moving about the community, walking, and climbing stairs. Reduction in mobility, as shown through this study, then impacts a patient's ability to perform ADL and IADL tasks, compromising the patient's self-care agency and the patient's ability to achieve self-care. It is for this reason that the symptoms experienced by patients should be addressed swiftly to either eliminate the symptom occurrence or at the very least, diminish its severity. The results from this study have shown that as the severity of symptoms increase, the patients mobility decreases. Therefore, the APN's inquiry of symptom severity should also include questions as to whether the patient and/or caregiver feels that the severity of these symptoms impedes the patient's mobility about the house and community. For clarity of limitation, the APN should list specific tasks such as their ability to lift or carry groceries, participate in moderate to vigorous activities, climb one to several flights of stairs, walk one block to over a mile, and their ability to bend, kneel, and stoop. Explicit information as to the current limitation experienced and previous level of functioning are necessary to determine the patient's baseline mobility level and the degree of the new impairment.

The advanced practice nurse's ability to reveal limitations in a patient's mobility will also provide insight into potential limitations in other areas of a patient's functional ability. This study showed that a patient's current mobility is the greatest indicator for the need for assistance with activities of daily living and instrumental activities of daily living. This finding indicates that as a patient's mobility decreases, the likelihood of the patient requiring assistance with ADLs or IADLs will increase. Therefore, once limitations in mobility are ascertained, the APN must evaluate the patient's ability to perform ADLs and IADLs. Again for clarity, a specific task list should be presented (i.e., bathing, eating, dressing, toileting, walking inside the home, transferring in and out of bed, laundry, cooking, housework, shopping, and transportation) to the patient and caregiver to determine which activities are limited. Results of this study showed that the APN should keep in mind that if limitations in mobility have been found, the patient is likely to have deficits in his/her ability to perform ADLs and IADLs. To assist in the assessment of need with functional ability, the APN must use their clinical expertise in determining that as the age of the patient increases, the likelihood of the need for functional assistance increases. The medical history of the patient should also be incorporated into the assessment of mobility, with the APN addressing the increased risk for functional decline in patients with comorbid diseases due to exacerbation of previous conditions related to the patient's current treatment regime.

Interventions for limitations in mobility, ADLs, and IADLs begin immediately after surgery during the patient's in-patient stay, when the nurse must physically assist the patient with his/her functional activities. Assistive tasks for patients with decreased mobility immediately post-op may include transferring the patent in and out of bed, grooming tasks such as bathing and/or dressing, and walking inside and outside of the room. The advanced practice nurse must continue to assess the patient's mobility in preparation to be discharged from the hospital. The assessment should include the patient's need for further rehabilitation (either on an in-patient or outpatient basis) and/or the need for assistive devices for mobility to be used in the home, such as the need for a cane or walker. Collaboration with physical therapy should be utilized to provide education and demonstration on the use of this equipment. Prior to discharge, the APN should assess the home environment through interviews with the patient and caregiver to determine if there are needs in the home, such as if a bar is needed in the shower to assist with transferring, or how many stairs the patient needs to manage at home.

The APN should collaborate with the patient and caregiver in determining a plan of action from this assessment regarding planned activity at home which coincides with the patient's mobility status. If the patient's bedroom is upstairs, plans may be made for the patient to sleep downstairs until he/she increases their strength. The necessity for education and training of family members in skill acquisition such as transferring the patient in and out of bed, assisting with colostomy care, applying depends on an incontinent patient, or preparation of meals that may decrease nausea and provide optimal calories for the maintenance of the patient's nutritional status, is an important part for the APN in the interventions necessary for a patient who is limited in any or all components of functional ability. Re-evaluation and reassessment are an integral part of the APN's role in the recovery of these patients. Treatment plans must be revised and updated to reflect the needs of the patent and their families until a full recovery and return to mobility has been achieved.

The assessment of resources available to the patient and caregiver, such as family, friends, church groups, or other support networks should be determined by the APN for an evaluation of their ability to continue with their cancer treatment regimen. The APN must assess the need for outside resources such as home care, meals on wheels, transportation services, or visiting nurses to assist the patient and family with limited support for these activities. Evaluation of the financial resources of the patient, including insurance coverage, will assist the APN in determining their fiscal risk of no continuing with the prescribed treatment for their cancer due to limited resources. Once fiscal need has been identified, the APN can connect the patient and caregiver with resources in the community that may provide the needed assistance. Through examination of all resources available to the patient and addressing any areas of deficit, the APN can increase the patient's ability to carry through with the prescribed cancer treatment.

The advanced nurse practitioner's role of case manager is much needed in assisting patients and their families in coordinating their treatment regimens. The treatment phase of cancer often involves weekly to daily treatments, lab visits, and follow-up appointments. APNs can work with the patient and the caregiver to set up appointments at the time of day when the patient feels his/her best, such as in the morning or in the afternoon after a nap. APNs can also assist the family in coordinating other services, such as home care or meals on wheels. The advanced practice nurse can also serve as a resource for the patient, family, and other supportive services to assure continuity of care and communication between all involved providers of care. Continual assessment and evaluation of the health care regimen is required of the APN to determine if expected outcomes are being achieved and if the plan of care needs to be adjusted.

It is important for the APN to encourage the patient and caregiver in expressing their feelings and concerns regarding the diagnosis of care and the effects of the disease. The patient should be encouraged to express feelings related to the diagnosis of cancer itself, contending with multiple symptoms, coping with an alteration in physical functioning, and potential feelings of helplessness during this time of acute illness. Caregivers should be encouraged to express their feelings related to being placed in the caregiving role and any frustrations with attempting to help the patient manage symptoms at home. Providing emotional support for both the patent and caregiver is an essential element of the APN's role. 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, or music therapy that will aid in their ability to cope with their current situation.

The APN must continually advocate for both the patients and caregivers during this time of cancer treatment. If the APN's first contact with the patient and caregiver is after the initiation of treatment for their cancer, the APN may assess the need to initially take a more directive role in the care of the patient. This may be necessary if the patient and caregiver are temporarily overwhelmed by the diagnosis of cancer and the implications of treatment intervention on the patient's health. The APN can then assist the patient and caregiver in maneuvering within the health care system and obtaining any needed services. Serving as advocate includes eventually transferring the responsibility of the patient's care back to the patient and caregiver. The APN will continue to collaborate with the family and other health care disciplines, provide education for the patient and other members of the family, provide support and counseling and assist in problem-solving as needed, however, the APN's ultimate goal is to transfer responsibility of health care to the patient and caregiver to promote the patient's self-care abilities.

Recommendations for Future Research

Currently, there is little research that examines the impact of the number and severity of symptoms on the functional ability of patients diagnosed with colorectal cancer. Therefore, there is a great need to continue this author's line of research. To establish greater validity and generalizability for this line of inquiry, future studies should involve a larger sample size, which should include a larger minority representation and recruitment of patients through physician offices to include equal representation of surgery only, and surgery with adjunctive treatments, inclusion of comorbid conditions, and an examination of the number of patients on Medicare and Medicaid. Inclusion of comorbid conditions would address compounding factors of symptom complaints, functioning ability, and cancer convalescence. Examining the insurance of the participants may help to identify barriers to cancer treatment or assistive resources. Instrumentation limitation can be addressed by removing the evaluation of walking from either the ADL or mobility scale, running the reliability analysis from the scale which walking was removed, and then run statistical analyses from the new scale. Following these recommendations would increase validity and generalizability of the research and also address limitations of this current study.

The suggested course of future research would examine the type, number, and severity of symptoms over a larger period of time, such as one year or more. Longitudinal research would provide information regarding the fluctuation of the type, number, and severity of symptoms over the course of treatment. This would further examine the work by Love et al. (1989) and assist in predicting the course of the cancer experience and assist in developing a plan of care. Further analysis, by grouping the type, number, and severity of symptom complaints according to the treatment modalities the patients are undergoing (surgery, chemotherapy or radiation therapy), will add further knowledge regarding which symptoms are more likely to occur with each treatment and if fluctuations occur as each treatment continues over the year.

Future studies should also examine the effect of symptom count and severity on functional ability over a longer period of time, such as a year or more. This would be helpful in determining if the number and severity of symptoms will eventually have a direct impact on ADLs, IADLs, and/or mobility as the course of cancer treatment continues. Examination of the impact of surgery on mobility as the course of cancer treatment continues. Examination of the impact of surgery on mobility should also be included in this future work. Results from longitudinal research of this line of inquiry will assist health care professionals in the development of treatment plans that will be better tailored to patients throughout the course of treatment, instead of patchwork information from multiple studies gathered at various times of cancer treatment.

Future studies could also examine symptom treatments and interventions. Research along this line of inquiry would provide information about the current treatment regimens and interventions aimed at relieving or lessening a patient's symptoms, and examining if relief of symptoms occur, and what percent success rate is involved with the interventions. The interventions examined could be pharmacological or adjunctive therapies, such as therapeutic touch. Benefits for this line of inquiry would be to statistically determine if our current practices are clinically based, continued out of proven efficacy, or if the interventions are continued out of habit. Proven and improved interventions for symptom treatment and prevention would be the ideal outcome for this line of research.

Future research should also extend to examine patients with a functional disability and the services they are receiving for assistance throughout the course of their cancer treatment. Evaluation can include if supportive services are being utilized, what barriers are preventing the utilization of supportive services, and if these services are formal or informal. Information generated from this study would determine if patients requiring assistance with functional abilities are receiving help, and if not, what barriers are preventing these services. A study of this nature will help to determine if a patient is receiving assistance if needed and who provides the assistance, and then it would use the results to improve the ability of APNs to connect patients with the needed agencies.

Summary

This study illustrated the wide variety of symptom complaints experienced by colorectal cancer patients at the time of treatment initiation. This study also described the ten most frequently occurring symptoms of these cancer patients, and their perceived average severity. The findings were consistent in identifying the most frequently occurring symptoms of patients with a solid tumor or lymphoma as fatigue, pain, poor appetite, and constipation. Included in the list of symptoms and consistent with literature are symptoms related to the chosen treatments for colorectal cancer. Symptoms such as nausea, diarrhea, urinary frequency, and vomiting may result from radiation or chemotherapy treatments.

A patient's mobility was found to be the greatest indicator of the need for assistance with activities of daily living and instrumental activities of daily living. Symptom severity and the patient's age were found to directly impact a patient's mobility. Therefore, it was found that the severity of the symptoms experienced and a patient's age impacts mobility, which then impacts ADLs and IADLs.

As cancer treatment regimens shift from in-hospital settings to outpatient clinics, responsibility for the day to day management of patient falls on the family. In order to assist the patients and families in providing care in their homes, it is necessary to understand the physical experience of cancer. This study has described many of the most frequently occurring symptoms, which have known etiologies and a manageable level of severity for most patients. It is with this knowledge that advanced nurse practitioners can provide anticipatory guidance in the prevention or early treatment intervention for these symptoms. Prompt intervention and home management of symptoms, such as rest periods or scheduled toileting, will help to diminish the severity of the symptoms and prevent physical activity impairment.

Advanced practice nurses can provide the needed comprehensive assessment knowledge, case management skills, and holistic approaches to health care to respond to the variety of needs of this cancer population. APNs, as clinicians, collaborators, advocates, and educators must position themselves to proactively respond to these needs and lead other health care professionals in providing comprehensive care.

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LIST OF REFERENCES

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APPENDIX A

UCRIHS APPROVAL FOR
THIS project EXPIRES:

JUN 05 1996

and must be renewed within
11 months to continue.

Michigan State University 9/95

MSU FAMILY HOME CARE CANCER STUDY

PATIENT CONSENT FOR RESEARCH

Introduction

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

This study is being conducted by Drs. Barbara and Charles Given who are professors in the College of Nursing and the Department of Family Practice at Michigan State University. This study is being sponsored by Michigan State University and also involves other hospitals or medical centers. This study will involve 1235 patients 65 years of age and older who have breast, colon, lung or prostate cancer.

Description of Procedures

Should you decide to participate you will be contacted by telephone four times over the next 12 months; at approximately 4, 12, 24 and 52 weeks following your diagnosis. The trained interviewer who will call you will ask you a number of questions about your health and how you are feeling, the types of activities you are able to perform for yourself and those with which you need help, and about your current financial status. It will take about 45-60 minutes to complete each interview. In addition, a written questionnaire will be sent to you with a stamped return envelope. This questionnaire will ask questions regarding your physical functioning, use of services, and out of pocket and related costs for cancer care. The questionnaire will take about 15-20 minutes to complete.

During the interview, you will be asked for the name and telephone number of the person who assists most with your care. This person will be contacted by telephone and asked the same types of questions as described above and to fill out and return a similar written questionnaire. This person will be contacted at the same times as you; at approximately 4, 12, 24 and 52 weeks following your diagnosis.

In addition, a member of the research staff will review part of your current medical record to obtain a list of your medical diagnoses/problems, and treatment(s) you are receiving for your cancer or other health problems. Information will also be obtained from the Health Care Financing Administration and other health insurers. This information will include admissions to hospitals, nursing homes and/or home care agencies, how long you received care in each of these, and the amount of money paid by Medicare for these services.

Risks and Discomforts

It is not expected that you or your caregiver will be placed at any physical, financial or legal risk as a result of participation in this study. Regardless of whether or not you choose to participate in this study, you will continue to receive medical care under the direction of your personal physician(s). All information collected for this study including that obtained from your caregiver, your medical record, the Health Care Financing Administration, interviews and questionnaires will be kept strictly confidential.

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

Benefits

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

Alternatives

If you decide not to participate in this study you will continue to receive all medical care and other forms of support. Neither you nor your caregiver will be contacted for telephone interviews or asked to complete questionnaires. In addition, information will not be collected from your medical record or the Health Care Financing Administration.

Rights and Responsibilities

To take part in this study, you must choose to do so and sign this form on the line below. Only volunteers will be used in this study. If you choose to be in the study now, you may withdraw later on by calling Dr. Charles W. Given at (517) 353-3843 or toll free, 1-800-654-8219. If you choose not to take part in this study, or if you withdraw after you have started, you will not be penalized in any way, nor will the quality of care you receive be affected. The investigators will keep you informed of any new developments that may affect your willingness to continue taking part in this study.

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

In the unlikely event of any injury from the research, no reimbursement, compensation or free medical treatment is offered by Michigan State University. Your hospital and/or medical care will continue under the direction of your physician, in accordance with your own particular financial arrangements.

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

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

Patient's Signature________________________________Date____________Time________

Please print:

name ____

address____

____

phone (______)________________________________

Investigator's Signature____________________________Date____________Time________

Witness' Signature________________________________Date____________Time________

APPENDIX B

THIS project EXPIRES

JUN 05 1996

and must be renewed within
11 months to continue.

Michigan State University 9/95

MSU FAMILY HOME CARE CANCER STUDY

CAREGIVER CONSENT FOR RESEARCH

Introduction

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

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

Description of Procedures

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

Risks and Discomforts

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

It is recognized that the diagnosis and treatment of cancer is stressful. In over 400 cancer patients, the

APPENDIX C

MICHIGAN STATE
UNIVERSITY

February 13, 1997

TO: Barbara A. Given
A230 Life Sciences

RE: IRB#: 97-032
TITLE: COLORECTAL CANCER: THE SYMPTOMS EXPERIENCED AND HOW THEY AFFECT THE PATIENT'S FUNCTIONING ABILITY
REVISION REQUESTED: N/A
CATEGORY: 1-E
APPROVAL DATE: 02/11/97

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

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

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

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

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

Sincerely,

David E. Wright

David E. Wright, Ph.D.
UCRIHS Chair

DEW:bed

cc: Pamela J. Chuey

OFFICE OF
RESEARCH
AND
GRADUATE
STUDIES

University Committee on
Research Involving
Human Subjects
(UCRIHS)

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

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

APPENDIX D

NINR/NCI WAVE I PATIENT W/O CAREGIVER TELEPHONE

ID_ _ _ _/INT_
DATE_ _/_ _/_ _.

PATIENT SYMPTOM EXPERIENCE

The following is a list of symptoms that <u>some</u> people with cancer experience either from the illness or as a result of treatment.
If you have not experienced the symptom <u>in the past two weeks</u>, answer NO.
If you have experienced the symptom <u>in the past two weeks</u>, answer YES, then identify how severe this symptom was, indicating the severity of this symptom, either 1 = MILD, 2 = MODERATE, or 3 = SEVERE.
Finally, we will ask you to identify the extent this symptom has caused you to limit your regular activity, either 1 = NO EXTENT, 2 = SMALL EXTENT, 3 = SOME EXTENT, 4 = GREAT EXTENT, or 5 = VERY GREAT EXTENT.

We appreciate your helping us understand the impact of any symptom you may experience.

(Leave any category blank in columns B & C if symptom not experienced.)

	A. Did you experience this symptom in the <u>past two weeks</u>? (circle one)		B. If yes, how severe is this symptom for you? (circle one if experienced)			C. To what extent has this symptom disrupted or caused you to limit your regular daily activities? (circle one)				
SYMPTOMS	YES (1)	NO (2)	MILD (1)	MODERATE (2)	SEVERE (3)	NO EXTENT (1)	SMALL EXTENT (2)	SOME EXTENT (3)	GREAT EXTENT (4)	VERY GREAT EXTENT (5)
1. Nausea.	1	2	1	2	3	1	2	3	4	5
2. Pain.	1	2	1	2	3	1	2	3	4	5
3. Trouble sleeping.	1	2	1	2	3	1	2	3	4	5
4. Fatigue.	1	2	1	2	3	1	2	3	4	5
5. Difficulty breathing/ shortness of breath.	1	2	1	2	3	1	2	3	4	5
6. Diarrhea.	1	2	1	2	3	1	2	3	4	5
7. Coordination problems.	1	2	1	2	3	1	2	3	4	5
8. Vomiting.	1	2	1	2	3	1	2	3	4	5

NINR/NCI WAVE I PATIENT W/O CAREGIVER TELEPHONE

ID _ _ _ _/INT _
DATE _ _/_ _/_ _

(Leave any category blank in columns B & C if symptom not experienced.)

	A. Did you experience this symptom in the <u>past two weeks</u>? (circle one)		B. If yes, how severe is this symptom for you? (circle one if experienced)			C. To what extent has this symptom disrupted or caused you to limit your regular daily activities? (circle one)				
SYMPTOMS	YES (1)	NO (2)	MILD (1)	MODERATE (2)	SEVERE (3)	NO EXTENT (1)	SMALL EXTENT (2)	SOME EXTENT (3)	GREAT EXTENT (4)	VERY GREAT EXTENT (5)
9. Difficulty concentrating.	1	2	1	2	3	1	2	3	4	5
10. Weakness.	1	2	1	2	3	1	2	3	4	5
11. Dizziness.	1	2	1	2	3	1	2	3	4	5
12. Numbness, tingling, loss of feeling.	1	2	1	2	3	1	2	3	4	5
13. Poor appetite.	1	2	1	2	3	1	2	3	4	5
14. Weight loss.	1	2	1	2	3	1	2	3	4	5
15. Fever.	1	2	1	2	3	1	2	3	4	5
16. Cough.	1	2	1	2	3	1	2	3	4	5
17. Dry mouth.	1	2	1	2	3	1	2	3	4	5
18. Constipation.	1	2	1	2	3	1	2	3	4	5
19. Frequent urination.	1	2	1	2	3	1	2	3	4	5
20. Dehydration.	1	2	1	2	3	1	2	3	4	5
21. Mouth sores.	1	2	1	2	3	1	2	3	4	5

NINR/NCI WAVE I PATIENT W/O CAREGIVER TELEPHONE

ID _ _ _ _/INT_

DATE _ _/_ _/_ _

(Leave any category blank in columns B & C if symptom not experienced.)

	A. Did you experience this symptom in the past two weeks? (circle one)		B. If yes, how severe is this symptom for you? (circle one if experienced)			C. To what extent has this symptom disrupted or caused you to limit your regular daily activities? (circle one)				
SYMPTOMS	YES (1)	NO (2)	MILD (1)	MODERATE (2)	SEVERE (3)	NO EXTENT (1)	SMALL EXTENT (2)	SOME EXTENT (3)	GREAT EXTENT (4)	VERY GREAT EXTENT (5)
22. Itching.	1	2	1	2	3	1	2	3	4	5
23. Leaking urine.	1	2	1	2	3	1	2	3	4	5
24. Urgent need to urinate.	1	2	1	2	3	1	2	3	4	5
25. Hot flashes.	1	2	1	2	3	1	2	3	4	5
26. Breast tenderness.	1	2	1	2	3	1	2	3	4	5
27. Wake up at night to urinate.	1	2	1	2	3	1	2	3	4	5
28. Difficulty swallowing.	1	2	1	2	3	1	2	3	4	5
29. Sweats, night sweats.	1	2	1	2	3	1	2	3	4	5
30. Lack of sexual interest.	1	2	1	2	3	1	2	3	4	5
31. Bleeding, bruising.	1	2	1	2	3	1	2	3	4	5
32. Altered taste.	1	2	1	2	3	1	2	3	4	5
33. Mood changes.	1	2	1	2	3	1	2	3	4	5
34. Vaginal dryness (women only).	1	2	1	2	3	1	2	3	4	5

NINR/NCI WAVE I PATIENT W/O CAREGIVER TELEPHONE

ID _ _ _ _/INT
DATE _ _/_ _/_ _.

	A. Did you experience this symptom in the <u>past two weeks</u>? (circle one)		B. If yes, how severe is this symptom for you? (circle one if experienced)			C. To what extent has this symptom disrupted or caused you to limit your regular daily activities? (circle one)				
SYMPTOMS	YES (1)	NO (2)	MILD (1)	MODERATE (2)	SEVERE (3)	NO EXTENT (1)	SMALL EXTENT (2)	SOME EXTENT (3)	GREAT EXTENT (4)	VERY GREAT EXTENT (5)
35. Arm swelling	1	2	1	2	3	1	2	3	4	5
36. Limitations in arm movement	1	2	1	2	3	1	2	3	4	5
37. Leg swelling	1	2	1	2	3	1	2	3	4	5

APPENDIX E

ID ___ ___ ___ ___/INT ___
DATE ___ ___/___ ___/___ ___

The next set of questions asks about your ability to perform activities. I will state an activity and then read the definition before I ask you questions regarding the activity.

Activities of Daily Living

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 <u>to</u> bed clothing at night. This category DOES NOT include management of clothing during toileting. <u>If you wear bed clothing during the day, answer "NEVER DRESS</u>." Select the category that best describes your level of functioning for DRESSING.

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

___ **WERE INDEPENDENT – (did not need help of another person in any part of this activity) (1)**

___ **NEEDED SOME PHYSICAL HELP – (required physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATED (2)**

___ **NEEDED TOTAL PHYSICAL HELP – (needed another person to carry out this activity) CARE RECIPIENT DID NOT PARTICIPATE (3)**

___ **NEVER DRESSED (4)**

___ **NA/REFUSED (9)**

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

___ **ARE INDEPENDENT (Go to question 2) (1)**
___ **NEED SOME PHYSICAL HELP (Go to 1c) (2)**
___ **NEED TOTAL PHYSICAL HELP (Go to 1c) (3)**
___ **ARE NEVER DRESSED (Go to 2) (4)**
___ **NA/REFUSED (9)**

1c. Is the reason for this help related to ... (check one)

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

1d. If someone helps you with dressing, who helps ... (check all that apply)

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

1e. If the primary caregiver helps with dressing ...

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

_______ **Times per week**

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

_______ Minutes each time

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

1f. 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 patient doesn't know, then ask them to estimate as best they can.)

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

(1) 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 patient doesn't know then ask them to estimate as best they can.)

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

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

___ WERE INDEPENDENT - (did not need help of another person in any part of this activity) (1)

___ NEEDED SOME PHYSICAL HELP - (required physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATED (2)

___ NEEDED TOTAL PHYSICAL HELP - (needed another person to carry out this activity) CARE RECIPIENT DID NOT PARTICIPATE (3)

___ NOT APPLICABLE (needed tube feedings, IV's ONLY) (4)

___ NA/REFUSED (9)

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

___ ARE INDEPENDENT (Go to question 3) (1)
___ NEED SOME PHYSICAL HELP (Go to 2c) (2)
___ NEED TOTAL PHYSICAL HELP (Go to 2c) (3)
___ NOT APPLICABLE (Go to 3) (4)
___ NA/REFUSED (9)

2c. Is the reason for this help related to ... (check one)

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

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

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

2e. If the primary caregiver helps with eating ...

(1) In the past week, how many times did he/she help with eating? (write in)

_______ Times per week

(2) Approximately how long in minutes each time did he/she help with eating? (write in)

_______ Minutes each time

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

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

(1) 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 patient doesn't know, then ask them to estimate as best they can.)

(GO TO NEXT PAGE)

2g. If other paid helpers (family, friends, or professionals) help with eating ...

(1) 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 patient 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, soaping, rinsing, exiting, drying body. This does not include washing of head, drying hair, nor dressing or undressing. Select the response that best describes your level of functioning for bathing.

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

___ WERE INDEPENDENT – (did not need help of another person in any part of this activity) (1)

___ NEEDED SOME PHYSICAL HELP – (required physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATED (2)

___ NEEDED TOTAL PHYSICAL HELP – (needed another person to carry out this activity) CARE RECIPIENT DID NOT PARTICIPATE (3)

___ NA/REFUSED (9)

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

___ ARE INDEPENDENT (Go to question 4) (1)
___ NEED SOME PHYSICAL HELP (Go to 3c) (2)
___ NEED TOTAL PHYSICAL HELP (Go to 3c) (3)
___ NA/REFUSED (9)

3c. Is the reason for this help related to ... (check one)

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

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

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

3e. If the primary caregiver helps with bathing ...

(1) In the past week, how many times did he/she help with bathing? (write in)

_______ Times per week

(2) Approximately how long in minutes each time did he/she help with bathing? (write in)

_______ Minutes each time

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

3f. If other unpaid helpers (family, friends, or professionals) help with bathing ...

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

_______ Times per week

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

_______ Minutes each time

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

3g. If other paid helpers (family, friends, or professionals) help with bathing ...

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

_______ Times per week

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

_______ Minutes each time

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

(GO TO NEXT PAGE)

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

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

___ WERE INDEPENDENT – (did not need help of another person in any part of this activity) (1)

___ NEEDED SOME PHYSICAL HELP – (required physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATED (2)

___ NEEDED TOTAL PHYSICAL HELP – (needed another person to carry out this activity) CARE RECIPIENT DID NOT PARTICIPATE (3)

___ WERE UNABLE TO WALK – (would not bear weight) (4)

___ NA/REFUSED (9)

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

___ ARE INDEPENDENT (Go to question 5) (1)
___ NEED SOME PHYSICAL HELP (Go to 4c) (2)
___ NEED TOTAL PHYSICAL HELP (Go to 4c) (3)
___ ARE UNABLE TO WALK (Go to 5) (4)
___ NA/REFUSED (9)

4c. Is the reason for this help related to ... (check one)

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

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

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

4e. If the primary caregiver helps with walking inside the house ...

(1) In the past week, how many times did he/she help with walking inside the house? (write in)

_______ Times per week

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

_______ Minutes each time

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

4f. If other unpaid helpers (family, friends, or professionals) help with walking inside the house ...

(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 patient doesn't know, then ask them to estimate as best they can.)

4g. 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 patient doesn't know then ask them to estimate as best they can.)

5) TOILETING: This category includes: getting to and from the 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. This does not include assistance because of incontinence of bowel or bladder. Select the response that best describes your level of functioning for toileting.

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

___ WERE INDEPENDENT – (did not need help of another person in any part of this activity) (1)

___ NEEDED SOME PHYSICAL HELP – (required physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATED (2)

___ NEEDED TOTAL PHYSICAL HELP – (needed another person to carry out this activity) CARE RECIPIENT DID NOT PARTICIPATE (3)

___ NOT APPLICABLE – (had catheter, colostomy) (4)

___ NA/REFUSED (9)

ID ___ ___ ___ ___/INT ___
DATE ___ ___/___ ___/___ ___

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

___ ARE INDEPENDENT (Go to question 6) (1)
___ NEED SOME PHYSICAL HELP (Go to 5c) (2)
___ NEED TOTAL PHYSICAL HELP (Go to 5c) (3)
___ NOT APPLICABLE (Go to 6) (4)
___ NA/REFUSED (9)

5c. Is the reason for this help related to ... (check one)

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

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

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

5e. If the primary caregiver helps with toileting ...

(1) In the past week, how many times did he/she help with toileting? (write in)

_______ Times per week

(2) Approximately how long in minutes each time did he/she help with toileting? (write in)

_______ Minutes each time

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

5f. If other unpaid helpers (family, friends, or professionals) help with toileting ...

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

_______ Times per week

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

_______ Minutes each time

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

(GO TO NEXT PAGE)

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

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

6e. If the primary caregiver helps with transferring in and out of bed ...

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

_______ Times per week

(2) Approximately how long in minutes each time did he/she help with transferring in and out of bed? (write in)

_______ Minutes each time

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

6f. If other unpaid helpers (family, friends, or professionals) help with transferring in and out of bed ...

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

_______ 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 patient doesn't know, then ask them to estimate as best they can.)

6g. 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 patient doesn't know then ask them to estimate as best they can.)

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

5g. If other paid helpers (family, friends, or professionals) help with toileting ...

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

_______ 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 patient doesn't know then ask them to estimate as best they can.)

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

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

___ WERE INDEPENDENT - (did not need help of another person in any part of this activity) (1)

___ NEEDED SOME PHYSICAL HELP - (required physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATED (2)

___ NEEDED TOTAL PHYSICAL HELP - (needed another person to carry out this activity) CARE RECIPIENT DID NOT PARTICIPATE (3)

___ REMAINED BEDFAST (4)

___ NA/REFUSED (9)

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

___ ARE INDEPENDENT (Go to question 7) (1)
___ NEED SOME PHYSICAL HELP (Go to 6c) (2)
___ NEED TOTAL PHYSICAL HELP (Go to 6c) (3)
___ REMAIN BEDFAST (Go to 7) (4)
___ NA/REFUSED (9)

6c. Is the reason for this help related to ... (check one)

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

(GO TO NEXT PAGE)

Instrumental Activities of Daily Living

7) TRANSPORTATION

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

___ WERE INDEPENDENT – (did not need help of another person) (1)

___ NEEDED SUPERVISION – (required supervision and the presence of another during all or part of this activity) (2)

___ NEEDED SOME PHYSICAL HELP – (needed another person to help drive occasionally) (3)

___ NEEDED TOTAL PHYSICAL HELP - (needed others to drive) (4)

___ NOT APPLICABLE - (others have always done this) (9)

___ NA/REFUSED (9)

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

___ ARE INDEPENDENT (Go to question 8) (1)
___ NEED SUPERVISION (Go to 7c) (2)
___ NEED SOME PHYSICAL HELP (Go to 7c) (3)
___ NEED OTHERS TO DRIVE (Go to 7c) (4)
___ NOT APPLICABLE (Go to 8) (5)
___ NA/Refused (9)

7c. Is this due to your ... (check one)

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

7d. If someone helps you with transportation ... (check all that apply)

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

7e. If the primary caregiver helps with transportation ...

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

_______ Times per week

(2) Approximately how long in minutes each time did he/she help with transportation? (write in)

_______ Minutes each time

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

7f. If other unpaid helpers (family, friends, or professionals) help with transportation ...

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

_______ 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 patient doesn't know, then ask them to estimate as best they can.)

7g. 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 patient doesn't know then ask them to estimate as best they can.)

8) LAUNDRY

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

___ **WERE INDEPENDENT – (did not need help of another person in any part of this activity) (1)**

___ **NEEDED SOME PHYSICAL HELP – (required physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATED (2)**

___ **NEEDED TOTAL PHYSICAL HELP – (needed another person to carry out this activity) CARE RECIPIENT DID NOT PARTICIPATE (3)**

___ **OTHERS HAVE ALWAYS DONE THIS (4)**

___ **NA/REFUSED (9)**

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

___ **ARE INDEPENDENT (Go to question 9) (1)**
___ **NEED SOME PHYSICAL HELP (Go to 8c) (2)**
___ **NEED TOTAL PHYSICAL HELP (Go to 8c) (3)**
___ **OTHERS HAVE ALWAYS DONE THIS (Go to 8c) (4)**
___ **NA/REFUSED (9)**

8c. Is this due to your ... (check one)

___ Cancer or cancer treatment (Go to 8d) (1)
___ Other health problem(s) (Go to 8d) (2)
___ NA/Refused (9)

8d. If someone helps you with laundry ... (check all that apply)

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

8e. If the primary caregiver helps with laundry ...

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

_______ Times per week

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

_______ Minutes each time

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

8f. If other unpaid 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

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

_______ Minutes each time

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

8g. 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 patient doesn't know then ask them to estimate as best they can.)

9) **SHOPPING:** Includes all types of purchases.

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

___ WERE INDEPENDENT - (did not need help of another person in any part of this activity) (1)

___ NEEDED SOME PHYSICAL HELP - (required physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATED (2)

___ NEEDED TOTAL PHYSICAL HELP - (needed another person to carry out this activity) CARE RECIPIENT DID NOT PARTICIPATE (3)

___ OTHERS HAVE ALWAYS DONE THIS (4)

___ NA/REFUSED (9)

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

___ ARE INDEPENDENT (Go to question 10) (1)
___ NEED SOME PHYSICAL HELP (Go to 9c) (2)
___ NEED TOTAL PHYSICAL HELP (Go to 9c) (3)
___ OTHERS HAVE ALWAYS DONE THIS (Go to 9c) (4)
___ NA/REFUSED (9)

9c. Is this due to your ... (check one)

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

9d. If someone helps you with shopping ... (check all that apply)

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

9e. If the primary caregiver helps with shopping ...

(1) In the past week, how many times did he/she help with this shopping? (write in)

_______ Times per week

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

_______ Minutes each time

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

(GO TO NEXT PAGE)

ID __ __ __ __/INT ___
Date __ __/__ __/__ __

9f. 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 patient doesn't know, then ask them to estimate as best they can.)

9g. 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 patient doesn't know then ask them to estimate as best they can.)

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

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

___ WERE INDEPENDENT – (did not need help of another person in any part of this activity) (1)

___ NEEDED SOME PHYSICAL HELP – (required physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATED (2)

___ NEEDED TOTAL PHYSICAL HELP – (needed another person to carry out this activity) CARE RECIPIENT DID NOT PARTICIPATE (3)

___ OTHERS HAVE ALWAYS DONE THIS (4)

___ NA/REFUSED (9)

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

___ ARE INDEPENDENT (Go to question 11) (1)
___ NEED SOME PHYSICAL HELP (Go to 10c) (2)
___ NEED TOTAL PHYSICAL HELP (Go to 10c) (3)
___ OTHERS HAVE ALWAYS DONE THIS (Go to 10c) (4)
___ NA/REFUSED (9)

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

10c. Is this due to your ... (check one)

- ___ Cancer or cancer treatment (Go to 10d) (1)
- ___ Other health problem(s) (Go to 10d) (2)
- ___ NA/Refused (9)

10d. If someone helps you with housework ... (check all that apply)

- ___ primary caregiver (1) (Go to 10e)
- ___ paid family (2) (Go to 10g)
- ___ paid friends/others (3) (Go to 10g)
- ___ paid professional (4) (Go to 10g)
- ___ unpaid family (5) (Go to 10f)
- ___ unpaid friends/others (6) (Go to 10f)
- ___ unpaid professional (7) (Go to 10f)
- ___ NA/Refused (9)

10e. If the primary caregiver helps with housework ...

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

_______ Times per week

(2) Approximately how long in minutes each time did he/she help with housework? (write in)

_______ Minutes each time

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

10f. 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 patient doesn't know, then ask them to estimate as best they can.)

10g. If other paid helpers (family, friends, or professionals) help with housework ...

(1) 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 patient doesn't know then ask them to estimate as best they can.)

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

11) COOKING AND PREPARING MEALS

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

___ WERE INDEPENDENT – (did not need help of another person in any part of this activity) (1)

___ NEEDED SOME PHYSICAL HELP – (required physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATED (2)

___ NEEDED TOTAL PHYSICAL HELP – (needed another person to carry out this activity) CARE RECIPIENT DID NOT PARTICIPATE (3)

___ OTHERS HAVE ALWAYS DONE THIS (4)

___ NA/REFUSED (9)

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

___ ARE INDEPENDENT (Go to next section) (1)
___ NEED SOME PHYSICAL HELP (Go to 11c) (2)
___ NEED TOTAL PHYSICAL HELP (Go to 11c) (3)
___ OTHERS HAVE ALWAYS DONE THIS (Go to 11c) (4)
___ NA/REFUSED (9)

11c. Is this due to your ... (check one)

___ Cancer or cancer treatment (Go to 11d) (1)
___ Other health problem(s) (Go to 11d) (2)
___ NA/Refused (9)

11d. If someone helps you with cooking and preparing meals ... (check all that apply)

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

11e. If the primary caregiver helps with cooking and preparing meals ...

(1) In the past week, how many times did he/she help with cooking and preparing meals? (write in)

_______ Times per week

(2) Approximately how long in minutes each time did he/she help with cooking and preparing meals? (write in)

_______ Minutes each time

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

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

11f. 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)

_______ 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 patient doesn't know, then ask them to estimate as best they can.)

11g. 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 patient doesn't know then ask them to estimate as best they can.)

(GO TO NEXT SECTION)

APPENDIX F

NINR/NCI WAVE I PATIENT W/O CAREGIVER TELEPHONE

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

Mobility of the Patient

1. The following questions are about the activities you might do during a typical day. First, I'll ask you about performing these activities 3 or more months ago, or before you were diagnosed with cancer, and then I'll ask you about these activities currently. Does your health limit your ability to do activities? If so, how much? (Circle one for each question — 3 months ago and currently.)

(Interviewer: Thinking back to date three months ago were you limited in ... because of your health? What about now? We are interested in your ability to do these activities.)

	Three months ago, or before you were diagnosed with cancer, did your health limit you in these activities?			Currently does your health now limit you in these activities?		
	Yes, Limited A Lot (3)	Yes, Limited A Little (2)	No, Not Limited At All (1)	Yes, Limited A Lot (3)	Yes, Limited A Little (2)	No, Not Limited At All (1)
a. Moderate activities, such as moving a table, bowling, or playing golf?	3	2	1	3	2	1
b. Vigorous activities, such as lifting heavy objects, participating in strenuous sports?	3	2	1	3	2	1
c. Lifting or carrying groceries?	3	2	1	3	2	1
d. Climbing several flights of stairs?	3	2	1	3	2	1
e. Climbing one flight of stairs?	3	2	1	3	2	1
f. Bending, kneeling, or stooping?	3	2	1	3	2	1
g. Walking one block?	3	2	1	3	2	1
h. Walking several blocks?	3	2	1	3	2	1
i. Walking more than a mile?	3	2	1	3	2	1
j. Bathing or dressing yourself?	3	2	1	3	2	1