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Predictors of Physical Functioning in Elderly Terminally Ill Cancer Patients

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Susan Kay Hoppough

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PREDICTORS OF PHYSICAL FUNCTIONING IN ELDERLY TERMINALLY ILL CANCER PATIENTS

By

Susan Kay Hoppough

A THESIS

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

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ABSTRACT

PREDICTORS OF PHYSICAL FUNCTIONING IN ELDERLY TERMINALLY ILL CANCER PATIENTS

By

Susan Kay Hoppough

For persons with cancer the period prior to death is often perceived as a time of distress and loss of physical function with little evidence to either support or refute this perception. For this study elderly patients during the first 24 weeks of the descriptive longitudinal study were assessed in the interview prior to death. Proposed predictors of loss of physical function include: site and stage of cancer, age, gender, comorbid conditions, and prior level of function. Outcome variables include measurements of physical function.

Significant predictors of physical function in the period prior to death include site of cancer, gender, and level of physical function at the time of diagnosis. Knowledge of these factors can help the advanced practice nurse develop appropriate interventions for the terminally ill elderly cancer patient in maintaining quality of life. Research implications include the development of a risk factor profile to provide the delivery of cost effective care. Copyright by Susan Kay Hoppough 1998 This study is lovingly dedicated to my husband, John, and my daughters Sarah and Anne without whose support this would have not been possible.

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INTRODUCTION

By the year 2030, persons aged 65 and older will comprise 21% of the population, placing increased demands on health services (Murphy & Hepworth, 1996). In an attempt to curtail soaring health care costs, early discharge of patients to home care settings has shifted increased responsibilities of care to patients and family members. Elder cancer patients with complex needs are some of those experiencing discharge to home care settings with the responsibility of care often falling on the shoulders of equally frail spouses. Within this group of elder cancer patients are those in the terminal phase of their illness those patients with a physician-certified prognosis of six months or less to live (Mor & Masterson-Allen, 1990)-who have elected to remain at home to die. Services available to assist terminally ill patients and families are provided through hospice. Inherent in the hospice philosophy is the desire to assist the hospice patient and their family maintain quality of life in their dying days with care that includes symptom management, teaching, medical, nursing, and spiritual care (Laferriere, 1995).

It has been estimated that by the year 2030 over 6 million individuals over the age of 65 will have cancer,

with more than 60% of all cancer deaths occurring in this age group (Schonwetter, 1996). In 1990 it was estimated that approximately 17% of deaths occurred at home with the group most likely to die at home being those individuals with malignancies (Schonwetter, 1996). The American Geriatric Society (AGS), 1997, has suggested the responsibility for quality of care issues for the terminally ill patient lie within the health care system. Of the ten areas designated by the AGS as requiring accountability by the health care system, one specifically addresses the need to improve the preservation of physical functioning and ensuring autonomy, so that individuals might maintain personal dignity and self-respect (Marwick, 1997). One goal of advanced practice nursing is to assist the patient attain to the maximum level of function within their current health state (Fawcett, Tulman, & Samarel, 1995), therefore, individualized care of the terminally ill patient must include strategies that address physical function to improve quality of life. Determining and predicting levels of physical function in the terminally ill elder cancer patient will assist the advanced practice nurse to develop interventions specifically directed at maximizing and maintaining the physical function of the patient for as long as possible, thereby addressing one quality of life issue at this final phase of life.

Background of the Problem

While many authors have addressed care of the terminally ill geriatric cancer patient and quality of life issues (Schonwetter, 1996; Herbst, Lynn, Mermann, & Rhymes, 1995; Hirsch, 1995; Morrison & Morris, 1995; McMillan, 1996; Mor & Masterson-Allen, 1987; Greisinger, Lorimor, Aday, Winn, & Baile, 1997), others have addressed topics related to physical function in the geriatric cohort (Gompertz, Pound, & Ebrahim, 1994; Berkman, Shearer, Simmons, White, Robinson, Sampson, Holmes, Allison, & Thomson, 1996; Finch, Kane, & Philip, 1995; Van Hook, Berkman, & Dunkle, 1996; Rueben, Valle, Hays, & Siu, 1995). The relationship between end of life care and quality of life issues as they relate to physical function for the geriatric cancer patient in the period preceding death has received little attention. Study Purpose

This study specifically addresses predictors of the loss of physical function including the site of cancer, stage of cancer, age, gender interval of time between the interview and the time of death, comorbid conditions, and prior physical function of the patient at the time of diagnosis. The construction of four categories of physical function in the intermediate period prior to death will be developed.

Quality of life issues are most important during the terminal phases of the cancer trajectory. The concept of quality of life is multidimensional including, physical,

social, emotional, and family well-being issues, with cancer patients reporting being least satisfied with the physical functional aspects of the concept in the end of life (McMillan, 1996). Therefore, it is imperative to predict components of physical function amenable to interventions in order to improve the quality of life for the <u>terminally ill</u> cancer patient. This information can then be used by advanced practice nurses and other health professions to predict patient needs and develop interventions specifically directed at physical function to help quality of life. Conceptual Definitions

The following concepts will be studied in relationship to their impact on physical function prior to death including: site and stage of cancer; treatment modalities; comorbid conditions; and prior physical function levels.

Site and Stage of Cancer. It has been estimated that as the population ages there will be an increasing need to provide optimal care for the elderly <u>terminally ill</u> cancer patient. Currently, cancers discovered in the elderly are more likely to be in advanced stages of the disease and more than 60% of cancer deaths occur in the 12% of the population over 65 (Schonwetter, 1996).

Patients participating in this study were older adults, newly diagnosed with cancer as apposed to receiving a diagnosis of recurrent disease. The diagnosis of cancer, regardless of site, places the patient within a course of

treatment modalities marked by periods of symptom exacerbation and disability, with increasing dependency needs in the advanced stages of the disease (Given & Given, 1994). With the progression of cancer in the advanced stages, worsening symptoms influence the social and physical function of a patient (Kurtz, Given, Kurtz, & Given, 1994). Terminally ill cancer patients experience loss of physical function from both organ failure and/or symptoms. Organ failure can cause symptoms leading to loss of control of bodily functions and with independence and physical strength.

While cancer patients in the advanced stage of the disease may have common symptoms, evidence exists that at earlier stages the symptom profile is site and pattern of organ involvement dependent (Vainio & Auvinen, 1996). In a study of the prevalence of symptoms among patients with advanced cancer (Vainio & Auvinen, 1996), lung and breast cancer patients experienced at least moderate pain, patients with gynecological or head and neck cancers experienced moderate to severe pain, and those with the prevalence of severe pain highest in prostatic cancers. Gastrointestinal symptoms were most predominant in colorectal cancers, and shortness of breath most common in lung cancer. Poor functional status was most common in gynecological cancers and the primary sites reporting the highest levels of pain were also associated with poor functional status (Vainio & Auvinen, 1996). The symptoms experienced relate to the

primary tumor, which must be taken into account when evaluating the type of services that are most beneficial to optimizing functional status of a patient. The cancer sites included in this study are prostate, lung, colon, and breast cancer. Site and stage of cancer compared to physical function in the terminally ill cancer patient will be explored in this research to determine any significant relationships.

Treatment Modalities. Rather than concentrating on futile efforts to cure cancer in its final stages, it is the responsibility of health care providers to deliver palliative care to the terminally ill in a compassionate manner (Schonwetter, 1996). Palliative care may include surgical treatment, chemotherapy, or radiation therapy in an attempt to alleviate symptoms which may interfere with physical functioning by virtue of the inherent side effects of those treatments. While the prevalence of symptoms treated may vary with tumor site, pain is the most commonly feared symptom of advanced cancer. Other commonly reported treated symptoms include dyspnea, nausea and vomiting, and delirium when death is impending (Vainio & Auvinen, 1996). Therefore, physical function in the terminally ill patient may be impacted by the treatments given to alleviate symptoms with poor physical function associated with short survival rates than better physical function associated with longer survival rates (Vainio & Auvinen, 1996). In the study by Vainio and Auvinen (1996) the relationship between

physical function and short survival rates is unclear, however, the need for improved comfort measures, symptom management and skilled home care assistance to the patient and family is apparent as a integral part of treatment modalities. While treatment modalities are significantly related to physical function, they will not be addressed in this study because of the complexities involved.

Comorbid Conditions. Chronic diseases such as hypertension, cardiac disease, diabetes, and arthritis are examples of comorbid conditions that may contribute to limitations in physical function in older adults and those conditions exist even with treatment (Blaum, Liang, & Liu, 1994; Yancik, Havlik, Wesley, Ries, Long, Rossi, & Edwards, 1996). The existence of comorbid conditions and the life expectancy of the patient relative to those comorbid conditions may influence the type of treatment selected for the cancer patient. The life expectancy of an individual can be estimated from life tables and the presence, severity, or absence of comorbid conditions that may alter longevity (Fowler, Terrell, & Renfore, 1996). The significance of comorbid conditions in relationship to the cancer diagnosis is that other compromised organs and systems may influence the response to treatment modalities. Results of a study by Satariano and Ragland (1994) suggest that comorbidity in patients with breast cancer is related to the risk for death from causes other than breast cancer. However it is unclear if the comorbid conditions are the

cause of death from breast cancer or if the breast cancer and treatment may accelerate the course of the comorbid conditions making the risk for death from those conditions greater (Satariano & Ragland, 1994).

The mechanisms affecting the survival rates for women with breast cancer require further study with evidence suggesting that comorbidity has an independent effect on the prognosis for women diagnosed with breast cancer (Satariano, 1993). Clearly, the presence of internal factors, comorbid conditions, and the medications needed to treat those conditions place the elder at higher risk for complications from cancer treatments and may be detrimental to the overall, quality of life for the individual (Yanick et al., 1996).

Comorbidity within the larger study is measured through the extraction of information from medical records and interview questions. This medical record information was used to determine if the patient had a current diagnosis of osteoarthritis or other musculoskeletal disease; peripheral vascular disease; infectious disease; cardiovascular disease of any type; and any gastrointestinal disease in a manner similar to the comorbidity measurements done by Katz, Chang, Shangha, Fossel, and Bates, (1996). The comorbidity information was used in the Family Home Care for Cancer-A Community-Based Model, Grant # R01-NR01915 to determine the risk for survival within the population studied.

Prior Physical Function. It is the loss of physical function and need for personal and physical assistance which forces caregivers to opt for hospitalization of dying loved ones, away from the comforts of home. Function includes the ability to perform biological, psychological, and social activities normally expected of an individual at certain age, and the actual performance of those biological, psychological and social activities (Fawcett et al., 1995). Physical function encompasses the ability to, and actual performance of, activities. An inability to perform an activity in the manner considered normal is a limitation in physical function. Function is influenced by internal factors (symptoms associated with normal life transitions or chronic disease), external factors (family members or health care providers), and cultural factors (beliefs, norms, and values of a particular group) (Fawcett, Tulman, & Samarel, 1995). Functional Status is the "score" by which a patients physical function abilities can be measured and compared. Measurements include the SF-36, IADLs, and ADLs.

It is important to differentiate between <u>functional</u> <u>limitation and functional disability</u> when discussing physical function because it is the disability which leads to dependence on others in meeting physical and personal needs. Functional limitation, defined as <u>restrictions</u> in performing physical activities differs from functional disability, defined as <u>difficulty</u> in carrying out activities in any domain of life (Lawrence & Jette, 1996; Verbrugge &

Jette, 1994). The pathway to disability includes pathology (a cancer diagnosis) which leads to impairment (anatomic or structural) that in turn leads to functional limitation (physical or mental), which leads to disability (difficulty in doing activities of daily living) (Lawrence & Jette, 1996). Functional limitations are a driving force in the disablement process and must be considered in the development of appropriate interventions. For example, the lung cancer patient may experience difficulty shopping for personal items because of shortness of breath (physical limitation), but may be able to do so with the use of oxygen and a motorized cart. As the shortness of breath progresses further limitations may lead to the person shopping less frequently or not shopping at all (disability).

Knowledge of the patients prior level of physical function is an essential element in determining the degree of loss of physical function in the terminal phase of the elder cancer patient. A greater feeling of loss may be experienced by those individuals whose prior level of function had been independent compared to those with already compromised levels of physical function. Individuals dependent in levels of physical function prior to the terminal phase of their illness may already have in place mechanism to deal with the dependence and therefore not feel the same degree of loss.

The pathway toward disablement and dependency for this study is measured through the use of the SF-36, IADLs, and ADLs. The proposed measurement of the progression of steps leading to disability includes: patients view of the effect of cancer on their physical function and quality of life (SF-36); the impact of the cancer on the patients ability to perform instrumental activities of daily living (IADLs); and finally, the impact of the cancer on basic activities of daily living (ADLs). The rationale for measuring all three levels of functions are to determine if assumptions can be made about the disability of an individual based on limitations in physical function.

The SF-36 assesses eight domains of function and wellbeing. For the purposes of this study those questions which assess specifically physical function as a result of physical health problems (cut down on the amount of time spent, accomplished less, limited in the kind of work or other activities done) will be used. Response options for the questions include a 3-point scale: limited a little, limited a lot, or not limited at all (Reuben, Valle, Hays, & Siu, 1995). The items selected from the SF-36 test perceived limitations in function that are viewed as determining quality of life related to physical function (VanHook et al., 1996), compared to levels of dependencies determined by the IADLs and ADLs.

The Instrumental Activities of Daily Living (IADL), measures the ability of a patient to maintain an independent

life style by accomplishing a set of complex tasks such as driving about the community, cooking, doing housework, shopping, and laundry. The measures include: independent (requires no assistance); need supervision only (requires another person present without regular assistance); need some physical (the care recipient participates); need total physical help (care recipient does not participate); and, others have always done the activity (Allen, Mor, Raveis, & Houts, 1993).

The Activities of Daily Living (ADL) measures basic activities required to sustain independent living such as bathing, dressing, eating, and toileting. Again, the measurement choices include: independent; need supervision only; need some physical help; or need total physical help.

While physical function may be used as a predictor of subsequent adverse effects for an individual, a "gold standard" for measurement of physical function does not exist. For this reason, the measurement of the complicated variable of physical function can best be served through the use of multiple tools (SF-36, ADLs, and IADLs) to avoid the under- or over- reporting of dependencies for a specific population (Rueben et al., 1995).

In summary, factors useful as predictors of disabilities of physical function in the end of life for cancer patients include the site of the primary tumor,

treatment modalities, comorbid conditions, and physical function measurements. It is important to determine these factors to develop interventions most beneficial in the assistance of cancer patients and their families in the terminal course of cancer. For the purposes of this study the specific patient characteristics which will be addressed as predictors of physical function will include age, gender, site of cancer, stage of cancer, comorbidity, and prior level of physical function. A limitation of this study will be that although treatment modalities may be regarded as significant in the physical function of these patients, the treatment modalities will not be addressed as predictors.

Statement of Purpose and Problems

The purpose of this study is to identify factors within a profile which will predict levels of physical function in elderly terminally ill patients newly diagnosed with solid tumors of either breast, colon, lung, or prostate cancer. Construction of four categories of physical function prior to death will enable the advanced practice nurse to correctly identify those elderly terminally ill cancer patients at risk for dependence, anticipate the needs and determine appropriate interventions directed at maintaining physical function for as long as possible. The four categories of physical function prior to death will include: 1) Independent, 2) Dependent in high level of physical function- the SF-36 physical function subscale- only, 3) Dependent in high level physical function (SF-36) and IADL's

and 4) Dependent in high level function (SF-36), IADL's and ADL's.

Specifically, the research questions to be addressed for this thesis are:

- 1. What factors (interval of time between the date of the interview prior to death and the date of death; age; gender; prior level of function; site of cancer; stage of cancer; and comorbidities) predict variations in the levels of physical function among cancer patients in the three months prior to their death?
- 2. Are there differences in the level of physical function experienced by males and females with lung or colon cancer in the months prior to their death?

Conceptual Framework

For the purpose of this study, it will be assumed that the physical function of cancer patients decreases with impending death and is influenced by other factors including: age; gender; site of cancer; stage of cancer; comorbidity; and functional status prior to diagnosis. This study is guided conceptually by the Treatment and Care Processes Model, part of the Family Home Care for Cancer--A Community-Based Model, supported by grant #R01-NR01915 (Given & Given, 1995).

The Treatment and Care Processes Model identifies treatment and care processes affecting outcomes of care for the patients involved (See Figure 1). Significantly, this model uses a flexible problem-solving approach to deliver



Figure 1. Treatment and Care Processes Model from grant #1R01-NR01915, "Family Home Care for Cancer--A Community-Based Model", funded by the National Center for Nursing Research, 1989. care. Patient and caregiver characteristics are viewed as influencing the processes of care with specific needs of the dyad for assistance from a cancer care intervention (CCI) identified. Other factors influencing the CCI include the types of modality used to treat the cancer diagnosis. These factors (patient and caregiver characteristics, processes of care, treatment modalities and CCI) influence the outcomes of care for both the patient and caregiver and determine the use of the health care system by the individuals involved. Within this model, patients and caregivers of patients with cancer require assistance to produce desired outcomes (Given & Given, 1995).

Because the focus of this study is on the patient and not the caregiver only those areas of the conceptual model which pertain to the patient will be addressed (See Figure 2). Patient characteristics (age, gender, site and stage of cancer, comorbid conditions, and prior level of function) may directly influence the patient processes of care (the symptoms they report, the services they use and their return to prior function and rehabilitation use). Treatment modalities impact the patient processes of care. That is, the reporting of needs related to the treatment or disease and the way the needs are addressed, affect the quality of life experienced by the individual. The manner in which the patients needs are addressed may directly impact their ability to return to prior levels of <u>physical</u> function (SF-36, ADLs, and IADLs) or to maintain levels of <u>physical</u>





function in the terminal phase of the disease, thus improving quality of life for the individual (See Figure 2).

The focus of this study will be the patient characteristics and outcomes of care recognizing that other factors (processes of care, including treatment) may influence physical function, but are not included in the risk factor profile (See Figure 2). The patient characteristics include: age, gender, site of cancer, stage of cancer, comorbidity and prior function. Patient characteristics are important as predictors of physical function. All participants in the study are older than 65 and the prior functional limitations based on the aging process alone may influence physical function prior to death. Both males and females are included in the study and the differences in physical function experienced between the groups will be explored. The site of cancer may influence the physical function specifically related to the cancer or the treatment modality chosen. Comorbid conditions place patients at higher risk for decreased physical function and may be an essential predictor of physical function in the terminal phase of the cancer patient. Levels of physical function at the time of diagnosis are significant when discussing levels of physical function prior to death. Those individuals dependent at diagnosis, with established means to deal with the dependencies, may experience dependencies prior to death in a different manner than those who had previously been independent. Inclusion of the prior

level of function within a risk factor profile will help to determine the impact of prior levels of function on an individual during the terminal phase of cancer.

Physical function outcomes include patient statements in three categories: 1) performance in SF-36 Physical Function, specifically limitations in moderate activities, vigorous activities, lifting groceries, climbing stairs, bending, kneeling, or stooping, and walking distances; 2) dependence or independence in Instrumental Activities of Daily Living (IADL) including transportation, laundry, shopping, housework, and, cooking and preparing meals; and 3) dependence or independence in the Activities of Daily Living (ADL) of dressing, eating, bathing, walking inside the house, toileting, and transferring in and out of bed,

Using the SF-36, IADLS, and ADLS, four patient outcome categories will be developed to be used as predictors of physical function including: 1) Independent, 2) Dependent in high level of physical function -the SF-36 physical function subscale- only, 3) Dependent in high level physical function and IADLS, and 4) Dependent in high level function, IADLS, and ADLS. Within the proposed Predictor of Physical Function model (See Figure 2), physical function is represented on a trajectory from independence to dependence. Boxes representing the three measurements scales used are placed between the independent and dependent boxes, arranged in such a way as to illustrate higher levels of function to basic function. Arrows are placed to depict the flow from

independence to dependence between the three measures and within the individual measures themselves. It is proposed that as SF-36 scores decrease, patients will begin to report limitations in IADLs first, and will report limitations in ADLs last until the reported limitations lead to disability and dependence. The Predictor of Physical Function Model, can then be used to predict the level of function in other terminally ill elderly cancer patients with the intent to then develop appropriate care interventions (See Figure 2).

Review of the Literature

While it is expected that physical function will decrease with impending death, the identification of patient characteristics in the terminal course of the disease specifically related to physical function will assist the health care provider to determine appropriate interventions aimed at improving the quality of life for the patient. Researchers frequently use ADLs and IADLs as criteria to determine a patients ability to function in activities of daily living and instrumental activities of daily living (Lynn, Teno, Phillips, Wu, Desbiens, Harrold, Claessens, Wenger, Kreling, & Connors, 1997; Given et al., 1994; Houts et al., 1988; Kurtz et al., 1994; Berkman, Shearer, Simmons, White, Robinson, Sampson, Holmes, Allison, & Thomson, 1996; Mickus, Stommel, & Given, 1997; Mann, Ottenbacher, Hurren, & Tomita, 1995; Lindsey, Larson, Dodd, Brecht, & Packer, 1994; Atwood, Holm, & James, 1994; Gompertz, Pound, & Ebrahim, 1994; Mui & Burnette, 1994) and have been referred to in the

hospice literatures as indicators of quality of life (Hirsch, 1995; Mor & Masterson-Allen, 1987).

A review of the literature regarding care of the terminally ill cancer patient, comorbidity, and physical function in a variety of combinations is extensive. Even though the loss of physical function has been identified as a key element related to quality of life, there exists a gap in the literature as to what factors predict physical function in the elderly terminally ill cancer patient. The importance of knowing predictors of physical function in this population and the relationship of physical function to quality of life and costs to systems of care must be examined.

Patient Characteristics

The characteristics of age, gender, site, stage, comorbidity and prior levels of function are immutable. Placed within a risk profile these characteristics may help to predict levels of physical function prior to death. Patient characteristics are described within the demographics of most studies and have been linked to general unmet needs, frequently including ADLs.

Age, gender, site and stage of cancer

The relationship of age, gender, site of cancer and stage of cancer to physical function particularly in the elderly has received mixed attention. Many authors have addressed the relationship of symptom management (particularly, pain) to quality of life issues in patients

receiving hospice (McMillan, 1996; Mor & Masterson-Allen, 1990; Mor & Masterson-Allen, 1987; Schonwetter, 1996) without attention to physical function; while others have highlighted the importance of maintaining physical function (Houts, Yasko, Harvey, Kahn, Hartz, Hermann, Schelzel, & Bartholomew, 1988; Dudgeon, Raubertas, Doerner, O'Connor, Tobin, & Rosenthal, 1995; Given et al., 1994; Kurtz et al., 1994). To address the needs of patients with advanced cancer, Abraham, Callahan, Rossetti, & Pierre (1996), guided the development of teams of clinicians in Veterans' Affairs hospitals whose focus was to deliver expert palliative care. Some of the patient characteristics included in this study were age, gender, race and diagnosis. In this prospective study conducted in Philadelphia between 1993 and 1994 the team received 80 consultations, with complete data available on 75 patients. The heterogenous group consisted of African-Americans (60%), non-Hispanic white (37%), and Hispanic (3%), with 98% of the participants male. The primary diagnosis for 40% of the patients was lung cancer, followed by prostate cancer (22%), and gastrointestinal cancer (21%). Although age was listed as demographic information included in this study details were not reported specific to the patient population (Abraham et al., 1996).

The patient characteristics and unmet needs of the terminally ill cancer patient in the last month of life were addressed in a study by Houts, Yasko, Harvey, Kahn, Hartz, Hermann, Schelzel, and Bartholomew (1988). A stratified

random sampling of patients with a cancer diagnosis registered as dead in the state of Pennsylvania was conducted in a six month period of time in 1985. Stratification by age with groups from 20-39, 40-64, and >64 occurred to insure inclusion of the needs of young people. Of the 433 participants, 33% were over the age of 64, with no further information available about the demographic breakdown of this age group. Focus groups were conducted separately with the surviving family members to attempt to determine the unmet needs immediately after diagnosis and with persons terminally ill with cancer to identify unmet needs in the last month of life. Findings were similar between the groups. Within the group of persons with a cancer diagnosis, weighting of the sample results was done to match age, sex, and diagnostic characteristics. The most frequently reported unmet needs were ADLs (42%). Using logistic analysis to determine what patient characteristics were associated with unmet needs, independent variables included the deceased's age, sex, income before diagnosis, education, race, marital status, the geographic location of the death, number of days home in the last month, rural or urban home, and the site of the primary tumor (breast, lung, and colon). Physical unmet needs, described after weighting, were most frequently reported if the cancer patient was nonwhite, younger, had been diagnosed with breast cancer, and had spent more days at home in the last month of life (Houts et al., 1988).

The relationship between the patient characteristics of age, symptoms and survival status on the physical health of patients with cancer was examined by Kurtz, Given, Kurtz, and Given (1994) in a sample of 208 patient-caregiver dyads recruited in six community-based cancer treatment centers in Michigan. Adult patients included in the study were older than 20 years of age, newly diagnosed with a solid tumor or lymphoma or a recurrence of a previous diagnosis, and receiving treatment. The patients were divided into survivor groups and age groups to facilitate comparison of experiences at different stages of illness and age. Analysis of variance techniques were used to test for differences in means according to patient age and survivor groups. Results of the study included that higher-order function (immobility) is affected by both the nearness to death and the patients symptom experience but that limitations in ADLs (basic function) were affected solely by symptoms and not nearness to death (Kurtz et al., 1994).

The manner in which age, treatment, site of cancer and symptom experience affect physical function and mental health were examined by Given, Given, and Stommel (1994) in a longitudinal study of cancer patients aged 50 years and older (average age 63 plus or minus 7.3 years) over a 6 month period of time. The participants completed an intake survey and another questionnaire at 6 months to determine physical health using ADL measures as well as measures of symptoms and mental health. A terminal diagnosis was not a
variable studied in this research, and, for this group, age, gender and treatment protocols did not impact physical function. Instead, the symptom experience and changes in symptoms appeared to impact physical function over time. Stage of disease was not discussed in this study, but primary site of cancer did not impact physical function. However, the authors stress that if more lung patients had survived to 6 months other conclusions about physical function may have been drawn (Given et al., 1994).

Dudgeon, Raubertas, Doerner, O'Connor, Tobin, and Rosenthal (1995) looked at the needs of cancer patients with recurrence, identifying their physical needs in palliative rather curative terms. The median age of the group was 63 years (range 23-85) with 69-71% of the participants female. Seventy-five patients were recruited and placed in two groups: those with recurrent disease following curative surgery or radiation with or without adjuvant treatment; and a progressive group with disease progression following noncurative treatment. The responses to questions regarding severity of physical symptoms, emotional, psychological, social problems, and difficulties were evaluated. Greater physical needs and more severe symptoms were associated with more advanced disease and in terms of physical function the groups expressed difficulty with housework, leisure activities, and ambulation (Dudgeon et al., 1995). Specific links between physical function and symptom experience were not addressed. However, the authors suggest that patients

with advancing cancer require a continuum of care to meet changing needs throughout the disease trajectory as opposed to addressing physical, psychological, functional, and spiritual needs only at diagnosis or prior to death.

In summary, while age, gender, site and stage are mentioned as demographic factors related to physical function, specific details for each are under-reported (Greisinger et al., 1997; Abraham et al., 1996) making it difficult to draw comparative conclusions. Although some studies (Given et al., 1994; Dudgeon et al., 1995; Kurtz et al., 1994) have focused specifically the needs of elderly cancer patients, none have addressed age, gender, site and stage as risk factors related to physical function in the elderly terminally ill cancer patient. While most studies have used the cancer diagnoses of breast, colon, lung and prostate cancer, no studies looked at the differences in physical function experienced by elderly males compared to elderly females with the same diagnoses (lung or colon cancer). Determining the relationship of age, gender, site and stage of cancer to physical function as potential risk factors is essential.

Comorbidity

The relationship of comorbidity and physical function is of primary concern especially if the comorbid condition already impacts the physical function of an individual. The impact of cancer in the terminal phase of the disease and

the physical function of an individual can have profound effects and be greatly impacted by comorbid conditions.

Blaum, Liang, and Liu (1994), reported the relationship of comorbid conditions to service utilization in a study of 11,497 people aged 65 and over. Predictor variables included the chronic diseases of hypertension, arthritis, diabetes, cancer and atherosclerotic heart disease; selfrated health status; and disabilities. Control variables included gender, race, education, and social integration, with physician visits and hospital stays measuring outcome variables. Results of the study indicate that diseases may impact physical health status and the utilization of services differently. The authors identified problems associated with measuring and conceptualizing disabilities in physical function (IADLs) related to the lack of models measuring disability in all settings. Measurement issues arising from the use of self-reported chronic diseases related to the variables of interest was also identified as a limitation of the study (Blaum et al., 1994).

Other authors have attempted to describe the relationship of cancer and comorbidity in older patients in greater detail. Patients aged 65 and older experience agerelated comorbid conditions that once acquired, generally remain and are in themselves, disabling. Conditions such as arthritis, heart disease, diabetes, hypertension and COPD effect the complexity of treatment of cancer patients placing them at higher risk for adverse effects (Yancik,

Havlik, Wesley, Ries, Long, Rossi, & Edwards, 1996). Beginning in 1992, the National Institute of Aging (NIA), and the National Cancer Institute (NCI), began a study to determine what the nature of the comorbidity burden at the diagnosis of a malignancy is; and how do the concomitant conditions affect the diagnosis, treatment, and survival of cancer patients aged 65 and older. Populations of cancer patients were taken from those participating in the NCI Surveillance, Epidemiology, and End Results (SEER) Program who were diagnosed in 1992 with equal numbers of patients selected within the age groups of 55-64, 65-74 and \geq 75. Tumor site selection was based on three criteria: the predominant malignancies found in older patients (colon, breast, and prostate cancer); the prominence of the cancer with substantial incident differences related to gender (stomach, and urinary bladder cancer); and finally, age/stage differences at the initial diagnosis between the younger and older age groups and treatment variations related to age (ovarian and cervical cancer). Demographic information collected from medical records included age, gender, extent of disease, tumor history, first treatment course, and survival outcome. Comorbidity information was gleaned from physician notes, anesthesia notes, nursing records, discharge summaries, and a variety of laboratory reports. Preliminary results suggest that for most tumor sites, the proportions of comorbidities increase with advancing age.

Comorbidity and breast cancer issues have been addressed in a number of studies and a variety of perspectives including costs of care (Taplin, Barlow, Urban, Mandelson, Timlim, Ichikawa, & Nefcy, 1995) treatment (Newschaffer, Penberthy, Desch, Retchin, & Whittemore, 1996), survival (Satariano, 1993; Satariano & Ragland, 1994), and risk (Graves & Bland, 1995). None of the studies addressed the relationship between comorbidities and physical function in the breast cancer patient. A basic understanding of the relationship of these factors for women is essential because breast cancer is the leading form of cancer for women (Satariano, 1993).

Epidemiologic studies suggest the age adjusted incidence of breast cancer for women in the United States between 1986 and 1987 was 108.9 per 100,000 with the incidence increasing with age from 34.4 (<50 years of age) to 351.1 (> 50 years of age) per 100,000 (Satariano, 1993). After reviewing 463 breast cancer cases identified through the Metropolitan Detroit Cancer Surveillance System, Satariano (1993) concluded that women with two or more concurrent health conditions were 2.2 times more likely than those without comorbidity to die from their breast cancer, with heart disease being most problematic. The possibility exists that comorbid conditions have little effect on the course of the breast cancer, but that the breast cancer or treatment modalities may accelerate the course of the other

conditions thus increasing the risk of death from those diseases (Satariano & Ragland, 1994).

The impact of comorbidity on the life expectancy for men with localized cancer was addressed by Albertsen, Fryback, Storer, Kolon, and Fine (1996). Through the use of three previously validated systems (comorbidity indexes developed by Greenfield et al., Charlson et al., Kaplan & Feinstein), comorbidities were assessed to determine the predictability of mortality among men with clinically localized prostate cancer. A retrospective cohort of men aged 65 to 75 years who were identified by the Connecticut Tumor Registry and who were diagnosed with prostate cancer between 1971 and 1976 were studied. Using identifying information, the hospital of diagnosis, and treatment and the case disposition, as well as patient records chronicling comorbidities, the indexes were tested. A variety of analysis techniques were used to determine that Gleason scores and comorbidity indexes were highly significant predictors of mortality (p<0.0001) (Albertsen et al., 1996).

In summary, the impact of comorbidity on physical function in the terminally ill cancer patient should not be ignored. However, no studies addressed the relationship between comorbid conditions and the physical function of a terminally ill cancer patient. The impact on mortality must be considered whether the comorbid condition affects the type or tolerance of a treatment modality or whether the cancer and treatment impacts the course of the chronic

illness, or remains unaffected by the treatment. Either the cancer or the comorbid condition can lead to increased mortality and should be considered when determining appropriate interventions for the terminally ill elderly cancer patient.

Prior Physical Function

No studies reviewed addressed the level of physical function in the cancer patient at the time of diagnosis. One study discussed function serving as the basis to determine dependency and the need for long-term care services (Finch, Kane, & Philip, 1995) including measures of ADLs and IADLs. In this study, measures of function using the Katz ADL scale (alpha coefficient 0.85) assume equal weighting among six items: dressing, eating, bathing, walking inside the house, toileting, and transferring in and out of bed. Responses determine the level of independence and include: independent (doesn't require the help of another to complete the task), need supervision only (requires the assist of another occasionally in case of problems), need some physical help (requires physical help during all or part of the activity), or needs total physical help (need another person to carry out the activity) (Finch et al., 1995).

IADLs include: transportation, laundry, shopping, housework, and cooking and preparing meals. Levels of responses to determine dependency are the same as used in the ADL scale. In a descriptive correlational study by Whittle and Goldenberg (1996) conducted to determine the relationship between functional health status and IADLs in a group elderly people, a convenience sample of 47 subjects (>70 years of age) completed three questionnaires including the Multidimensional Functional Assessment IADL subscale. Results suggest that declines in social function, health perception and physical function are important indicators of overall health status, and that each could contribute to increased IADL dependency. The small sample size is recognized as a limitation by the authors with the suggestion that further studies be done to replicate the results (Whittle & Goldenberg, 1996).

ADL measurement as an indicator of the use of assistive devices by the elderly living in community settings was studied by Mann, Ottenbacher, Hurren, and Tomita, (1995). The purpose of the study was to determine the relationship of the use of assistive devices, pain, and functional status to the severity of physical illness the elderly disabled reported. One hundred and ninety-four elderly (mean age of 75.4) disabled persons (67.5% female; 89.7% white; 54.6% widowed; 75.3% had children; and 47.9% lived alone) recruited in the western New York region, were placed into one of seven groupings based on level of disability. Interviews conducted in the subjects home determined levels of function using a battery of assessment tools, one being the Functional Independence Measure (FIM) of ADLs. Results of the functional independence score indicate that as ADLs

decline physical disability increases. The authors note a limitation of the study because of the comparison of groups based on their physical disability rather than following the individuals over a period of time (Mann et al., 1995).

Elderly cancer patients experience varied levels of dependence during the disease and treatment course. Lindsey, Larson, Dodd, Brecht, and Parker (1994) conducted a longitudinal prospective study of 45 elderly (mean age 69.8 years) patients receiving radiation for either breast (42%) or lung (58%) to determine outcomes in a variety of variables including multidimensional functional status. Data collection points included the beginning, middle, and conclusion of therapy as well as three months post radiation with the goal of determining if there existed a significant difference between the subjects with comorbidity and those without for moderator (gender, caloric intake, adequacy of caloric intake, radiation dose, side effects, and social support) or outcome variables (weight, BMI, and functional status) during and after radiotherapy. Also, the authors were interested if there was a significant change in any of the outcome variables (weight and functional status) throughout the course of radiotherapy (Lindsey et al., 1994). Results of this study indicate that for patients receiving radiation consuming less than adequate nutritional intake, functional status was not disrupted.

The interaction effect of age, symptoms and survival status on the physical health of patients with cancer was

examined by Kurtz et al. (1994). One focus of the study was to determine how age and survival status influenced dependencies in physical function (as measured by the SF-36). Cancer patients (n=208) involved in treatment were interviewed over the course of one year with measures of their physical function recorded. After applying analysis of variance techniques it was determined that survival status had a direct effect on immobility. Recommendations were made to encourage the development of strategies directed at assisting patients deal with immobility issues (Kurtz et al., 1994). In a longitudinal study of 111 elderly cancer patients involved in treatment it was determined that primary site may impact limitations in function, that age and gender had no impact on function, but that symptoms experienced at intake and changes in those symptoms over time predicted physical function. No gender differences in physical function were found in this study (Given et al., 1994).

The SF-36 measure used in both of these studies was designed to determine how patients view physical function and its effect on their quality of life (VanHook, Berkman, & Dunkle, 1996). The studies by Kurtz et al. (1994) and Given et al. (1994) demonstrate that a variety of patient characteristics impact physical function as measured by the SF-36. Because the SF-36 measure addresses dimensions of quality of life related to physical function it is important to include the SF-36 when assessing patient needs.

In summary, the need to measure physical function using the SF-36, IADLs and ADLs and develop appropriate interventions to meet the identified needs has received attention from a variety of researchers (Finch et al., 1995; Whittle & Goldenberg, 1996; Mann et al., 1995; Mickus et al., 1997; Lindsey et al., 1994) for a variety of reasons. Berkman et al. (1996) have suggested that with the increasing numbers of elderly people and escalating health care costs, screening of the specific needs of individuals is essential and the use of IADL and ADL measurements are more likely to be predictive of interventions than other factors. Therefore, the need to measure physical function at the time of diagnosis and throughout the cancer care trajectory is essential. Using the SF-36, IADL and ADL measurements as predictors of physical function in the elderly cancer patient is one method of developing appropriate strategies to meet the needs of this patient group.

This study will identify the patient characteristics of terminally ill elderly cancer patients, and outcomes in physical function that could be used in the future to develop a risk profile to provide more information about the care requirements of the terminally ill cancer patient. By focusing on male and female patients with breast, lung, colon, and prostate cancer, differences can be identified which relate to their specific disease.

Methods

Research Design

The original study was a cohort of cancer patients and their caregivers recruited from a variety of sites through Michigan and Indiana. The Family Home Care for Cancer--A Community Based Model, Grant # R01 NR01915, is funded by the National Center of Nursing Research and the National Cancer Institute (NCI), Barbara A. Given, PhD, RN, FAAN, and Charles W. Given, PhD are the Principal Investigators. Collaboration between Michigan State University (MSU) College of Nursing, College of Human Medicine, Departments of Family Practice, Medicine and Surgery, the Cancer Center at MSU, and the MSU Cancer Treatment Consortium provided support. Data collected from structured telephone interviews and self-administered booklets with patients across a variety of waves will be secondarily analyzed to answer the research questions.

Study Sample

Participants in the original study were recruited from a variety of community cancer treatment sites in Michigan and Indiana. Criteria for inclusion were: elderly patients (> 65 years); newly diagnosed with solid tumor cancer either breast, lung, colon, or prostate; and currently receiving treatment (surgery, chemotherapy, or radiation therapy). Patients were asked to identify caregivers, but that will not be analyzed for this part of the study.

Those patients who died after completing Wave I and/or Wave II interviews and who died before completing a Wave III interview were included in the analysis. The interval of time to death was counted in number of days, determined by subtracting the date of death from the date of the last interview completed prior to death.

Staging data determined during audits of the patients records were used as a variable in this study, but was not used as a criteria of eligibility. While it is expected that all participants were late stage prior to their deaths, it cannot be assumed. Therefore, available staging information on the participants may range from early to late stage. Breast cancer is staged using the TNM staging system including tumor classification of Tis through T4, node classification N0, through N3 and the presence or absence of metastasis, M0 and M1, with the stage grouped then as Stage 0 through stage IV (Groenwald, Frogge, Goodman, & Yarbro, 1997).

Lung cancer is staged using the Veterans Administration classification of Limited or Extensive (small cell carcinoma) as well as TNM staging for non-small cell carcinomas including tumor classification of TX through T4, node classification of N0 through N3 and the presence or absence or metastasis, M0 through M1. Stage grouping includes Stage 0 through Stage IV (Groenwald et al., 1997).

Colon cancer is staged using the TNM staging including tumor classification of Tis through T4, node classification

of NO through N3, and the presence or absence of metastasis MO M1. Stage grouping includes Stage O through Stage IV (Groenwald et al., 1997).

Prostate cancer is staged using the TNM staging including tumor classification of TX through T4b, node classification of N0 through N3, the presence or absence of metastasis as M0 or M1, stage grouping including Stage 0 through Stage IV, and the Jewett staging system of Stage A through Stage D (Groenwald et al., 1997).

Data Collection Procedures

In the original study, patients aged 65 and older were systematically identified by personnel of acute care agencies or oncology centers and practices, who had been hired by the grant to identify patients who fit the study criteria. Nurses recruited those patients who met the criteria, explained the nature of the study to the patients and obtained signed consent. This consent provided authorization to review medical records, obtain address and telephone numbers as well as other clinical information needed for the purposes of the study. Those individuals giving written consent were observed for a one year period of time at specific intervals. During this time frame patients were contacted within six weeks of their original diagnosis and again at 12, 24, and 52 weeks. Telephone interviews were conducted using structured, closed ended questions. After completion of interviews patients completed mailed self-administered interviews.

Interviewers included graduate students who were nurses or medical students who received specific training to insure consistency of techniques and adherence to the protocol. Training for interviewers included: manuals which contained the study protocols, the CI3 computer program to facilitate following the protocols, mock interviews and taped mock interviews; taped actual interviews and; quality assurance review of 10% of the patient records for each interviewer monthly, with feedback provided by the PIs.

For this study, only the patient interviews served as a data source using information collected at the wave prior to death and at entry into the study. The questions used will focus on the patients perception of physical function within the categories described. Sociodemographic used included that collected at study entry.

Validity and Reliability

All methods used in this research have been previously tested by Given and Given in their work with elderly cancer patients. SF-36 (physical functioning subscale) has a reported alpha coefficient of .92, IADL of .91, and ADL of .85. SF-36 validity scores for individuals with chronic conditions have been reported at .87 (Ware, Kosinski, & Keller, 1994). ADL validity scores reported for elderly populations are .83 (Van Hook et al., 1996).

Operational Definitions

The independent variables for this study include: 1) the interval of time (between the date of the last interview

prior to death and the date of death); 2) age; 3) gender; 4)
site of cancer; 5) stage of cancer; 6) comorbidities; and 7)
prior level of function. Males and females are reported
separately if the diagnosis is lung or colon cancer.

Interval of time is reported in number of days as calculated by subtracting the date of death from the date of the last interview completed prior to death.

Sociodemographic information for this study includes age and gender. Age is reported in intervals of 5 year spans of time and include: 65-69 years; 70-74 years; 75-79 years; \geq 80 years. Gender is reported as males and females.

<u>Site of cancer</u> is reported as breast, lung, colon, or prostate.

<u>Stage of cancer</u> is reported as Early (Stage I and II) or Late (Stage III and IV).

Comorbid Conditions are reported by patients based on a set of responses to a specific list of medical conditions. The question asked if the patient had ever been told by a health care professional that they had any of the following problems including, but not limited to, stroke, hypertension, diabetes, etc. Comorbidities were then counted within ranges including: 0 (no reported comorbid conditions); 1-2 (reported comorbid conditions); 3 or more (reported comorbid conditions) after counts of "yes" and "no" are obtained.

The dependent variable for this study is physical function. Physical function is defined as the ability to

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participate in SF-36 activities, instrumental activities of daily living, and activities of daily living. Categories of physical function will include: 1) Independent; 2) Dependent in high level of physical function- the SF-36 physical function subscale-only; 3) Dependent in high level physical function and IADLs; and 4) Dependent in high level function, IADLs and ADLs. These categories of physical function are not found in the interview. Instead, final categories will be constructed based on distributions determined after analysis.

The <u>SF-36</u> category addresses the perception of limitations in physical function in 10 categories including: moderate activities; vigorous activities; lifting or carrying groceries; climbing several flights of stairs; climbing one flight of stairs; bending, kneeling or stooping; walking one block; walking several blocks; walking more than a mile and; bathing or dressing of self.

The <u>IADL</u> category includes the tasks of: transportation, laundry, shopping, housework, and cooking and preparing meals.

The ADL category includes the tasks of: eating, walking inside the house, toileting, and transferring in and out of bed. The activities of bathing and dressing will be covered in the SF-36 measurement.

<u>Measurement and Scoring</u>. Measurement tools used to collect the data from patients measuring physical function in the original <u>Family Home-Care for Cancer--A Community</u> **Based Study** included the SF-36, IADLs and ADLs (See Appendix A).

SF-36 measured perceived limitations in: 1) moderate activities; 2) vigorous activities; 3) lifting or carrying groceries; 4) climbing several flights of stairs; 5) climbing one flight of stairs; 6) bending, kneeling, or stooping; 7) walking one block; 8) walking several blocks; 9) walking more than a mile; and 10) bathing and dressing oneself. The SF-36 items and scales are scored in such a manner that a higher score indicates better health (Ware, 1993). To obtain the scaled score three steps are followed after data entry. First, items are recoded or the process of deriving the item values used to calculate the scale scores. The process of recoding changes any out of range values to missing; recodes values for the 10 items; and substitutes for missing items. Second, the scale scores are computed by summing across items in the same scale to obtain raw scale scores. After items are recoded and missing data is handled the raw score is computed for the scale by summing the responses for all items in that scale. For example the lowest and highest possible raw scores for physical function are 10 and 30. This range is determined by the responses given to the questions with a score of: "1" if the respondent selected "No, not limited at all"; "2" for "Yes, limited a little"; and "3" for " Yes, limited a lot". According to Ware (1993) this simple scoring method is possible because items within the same scale have

relationships equivalent to the underlying health concept being measured. Last, the raw score is then transformed into a scale score of 0-100 by using the following formula: Actual raw score minus the lowest possible raw score, dividing this by the possible raw score range (20) and multiplying the product by 100. This transformation converts the lowest and highest possible scores to zero and 100 representing the percentage of the total possible score. Ware (1993) provides specific directions to complete the scoring process. The SF-36 scaled score of 0 to 100, with 100 being high level of physical functioning, will be used to compare IADLs and ADLs. One disadvantage of using the SF-36 is the potential of under reporting of disability in telephone or personal interviews (McHorney, 1996). For this reason and others it is important to use more than one measure of physical function.

IADLS were measured by having the patient respond to levels of independence in 5 categories including: 1) Independent; 2) Needs supervision only; 3) Needs some physical help; 4) Needs total physical help; 5) Never dressed or Not applicable; and 6) Refused. For each choice of physical functioning the responses were coded as: "1" for independent; "2" for needs supervision only; "3" for needs some physical help; "4" for needs total physical help; "5" for never dressed or not applicable; and "9" for refused. Summated scores for items 1-4 ranged from 5 to 20. Responses to items 5 and 6 were reported separately to avoid

skewing the data. As supported by a review of the literature, the use of IADLs and ADLs subscales in combination are good indicators of dependency levels, and for this reason will be used within the context of this study as a predictor of physical function in the terminally ill elderly cancer patient.

ADLs were measured by having the patient respond to questions of independence in physical function, with 6 categories available including: 1) Independent; 2) Needs supervision only; 3) Needs some physical help; 4) Needs total physical help; 5) Never dressed or Not applicable; and 6) Refused. For each choice of physical function the responses were coded as: "1" for independent; "2" for needs supervision only; "3" for needs some physical help; "4" for needs total physical help; "5" for never dressed or not applicable; and "9" for refused. Summated scores for items 1-4 ranged from 6 to 24. Responses to items 5 and 6 were reported separately to avoid skewing the data.

Demographics include age and gender. Males were scored as "1" and females were scored as "2". Age was reported in 5 year spans of time with each age range reported as a percentage of the total. The mean age of the study participants and standard deviation were also reported.

Comorbidities were reported as: "0" no comorbidities; "1-2" comorbid conditions and " \geq 3" comorbid conditions. Each category was scored as: "1" for no comorbid conditions; "2" for `1-2' comorbid conditions or; "3" for " \geq 3" comorbid

conditions. Scores for comorbid conditions ranged from 1 to 3.

Each patient diagnosis was categorized by cancer type and stage. Each cancer type was reported as a percentage of the total population. Lung and colon cancer types were further broken down into percentages of females or males to determine if there are any gender biases related to physical function.

Categories of stage included "Early" or "Late" stage. "Early" included those patients with a I or II staging and "Late" included those patients with a III or IV staging. All "I's" and "II's" received a score of "1" and all "III's" and "IV's" received a score of "2". Stages were reported as percentages.

In order to classify patients according to their levels of physical function and to develop categories of data analysis sensitive to variations in physical function prior to death the following approaches were taken using the SF-36 physical function scale a sensitivity analysis was conducted to determine the point at which patients scores on physical function have 1-5 IADL dependencies and any ADL dependencies. The result will be the development of a classification system with no reported dependencies; dependency scores on SF-36 physical function alone; SF-36 physical function plus IADL; and the dependencies in SF-36, IADLs, and ADLs.

Data Analysis

The dependent variable for this study is physical function. The independent variables include cancer site, stage of cancer diagnosis, patient age, gender, number of comorbid conditions, and interval of death.

For research question 1, to determine what factors might predict variations in levels of physical function prior to death a multinomial logistic model was used to predict the four levels of physical function described. An ANOVA was applied to determine the differences in means of the groups. Cross tabulations were applied to determine if there is; cancer site effect on physical function; and effect of early or late stage on physical function. Mean scores and standard deviations for gender, age, site, stage, numbers of comorbid conditions, and interval of death, were compared to demonstrate changes in levels of SF-36 physical function three months prior to diagnosis and in the defined interval before death. Observed frequencies and percentages of the total sample will be presented to show the distribution of participants age, gender, site of cancer, stage of cancer and numbers of comorbid conditions.

For research question 2, cross tabulations were run on the independent variables to determine if there is a systematic gender effect on physical function.

Protection of Human Subjects

Participants in the Family Home Care for Cancer--A Community-Based Study were contacted initially during

hospitalization by recruiters who were part of the study staff. Information about the study was presented to them and they were asked if they were willing to participate. The participants physicians (including oncologists) were informed about the study. Signed consent forms were obtained (see Appendix B). Participants were allowed to refuse to answer any part of the study questions that they were uncomfortable with and were allowed to withdraw from the study at any time.

The original study was approved by the University Committee on Research Involving Human Subjects at Michigan State University with yearly review and approval conducted. Anonymity of each participant was assured by identifying each person with a number assigned at the time of study entrance. Only identifying codes are available on all questionnaires and records. The consent forms and identifying data are not available to the principal investigators.

Approval for secondary analysis was obtained from the Michigan State University Committee on Research Involving Human Subjects prior to data analysis (see Appendix C). A Subsample of the original sample was used with no further contact of the patient or caregiver made. Consent forms from the original study are on file and available to the Principal Investigators only. Data utilized included all information available prior to the patient death. Coded identifiers were only available, not subject identifiers.

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Any published information available will not report information about individuals.

Research Limitations

Research limitations include the small sampling of minority groups within the original study, leading to an even smaller representation in this subsample of terminally ill patients. Also, the study is from a self-select group of community-based residents and does not represent issues pertinent to those living in rural settings. The original study does not represent those who sought no treatment for their cancer.

A limitation of this secondary analysis includes the choice to not include treatment modalities as covariates and thus determine the relationship of treatment to the physical function of the terminally ill elderly cancer patient. This analysis also does not represent the specific needs of persons with early stage cancer, but those who died during the course of the study.

Another limitation involves the small sample size available of those patients who died within time frame set forth for this study making it difficult to generalize the information obtained to other populations.

Results

Description of the sample

The sample consisted of 57 patients, with more than half (n=34, 59.6%) male and more than half the total sample (n=37, 64.9%) were between the ages of 65-74. Most of the

patients were diagnosed with lung cancer (n=46, 80.7%) and with late stage cancer (n=41, 73.2%). More than half (n=29, 51.8%) of the patients reported 3 or more comorbid conditions (see Table 1).

Answers to Research Ouestions

1) What factors (interval of time between the date of the interview prior to death and the date of death; age; gender; prior level of function; site of cancer; stage of cancer; and comorbidities) predict variations in the levels of physical function among cancer patients in the interval of time prior to their death?

Using an ANOVA model, a one-way analysis of variance for interval levels of the dependent variable physical function scores from the SF-36 by each of the specified single factor (independent) variables was produced to determine trends across categories and specific contrasts. Due to missing values, only 48 observations were used for this analysis.

The ANOVA model was chosen to test the significance of differences between means (Polit & Hungler, 1995; Moore & McCabe, 1993), that is, to assess whether the observed differences among the sample means are statistically significant where $P \leq 0.05$. The ANOVA decomposes total variability of a set of data into two components: the variability resulting from the independent variable and other variability (individual differences or measurement unreliability for example). The null hypothesis tested

Table 1.

Frequencies and Percent of Sample Sociodemographic Variables

Demographic Variable	n	<u>₹</u>
Gender		
Fomalo	23	40.4
Male	34	59.6
Patient Age		
65-74	37	64.9
75 and above	20	35.1
Cancer Site		
Br/Co/Pr*	11	19.3
Lung	46	80.7
Diagnostic Stage		
Early**	15	26.8
Late***	41	73.2
	Frequency	Missing = 1
Reported Comorbid Conditions		
0-1	17	30.4
2 ·	10	17.9
3+	29	51.8
	Frequency	Missing = 1

*Breast/Colon/Prostate **Stage 0, I, or II ***Stage III or IV

within this model is that the SF-36 mean scores for each of the independent variables will be equal.

The statistic calculated in an ANOVA model is the Fstatistic that compares the variation among groups with the variation within groups (Polit & Hungler, 1995). The calculated value of the F statistic appears under the column labeled F-value (see Table 2) and its P value is under the heading P>F. For example, the value of F for gender is 5.85 Table 2.

Independent Variables	DF	SS	Mean Square	F-value	P> F
Gender	1	2764	2764	5.85	0.02
λge 75	1	555	555	1.17	0.28
Site	1	4155	4155	8.79	0.00
Stage	1	1194	1194	2.53	0.12
Comorbidity	2	438	219	0.46	0.63
Interval	2	2819	1409	2.98	0.06
PF 3M*	1	8518	8518	18.02	0.00
R-Square	0.51	SF-36	Mean 52.68		

ANOVA Model of Independent Variables Predicting Loss of Physical Function In Interview Prior to Death

* Physical Function 3 months before diagnosis

with a P value of 0.02 meaning that an F of 5.85 or larger would occur only 2% of the time by chance. Because the P value is small, the observed variation in the sample means cannot be attributed to chance. Therefore, it is possible to reject the null hypothesis for gender. Other variables in which the F value is significant are site of cancer (P=0.00) and physical function scores 3 months before diagnosis (P=0.00) (see Table 2). The R-square of .51 tells us that 51% of the variance in the dependent variable (physical function) can be explained by the independent variables.

Frequencies, means, and standard deviations are reported within each group for each independent variable (see Table 3). It was possible to determine the specific differences in physical function (SF-36) for those

Table 3.

Independent		SF 36	**	PF :	3 M *
Variable	n	Mean	SD	Mean	SD
Gender					
Female	20	53.2	24.6	61.9	27.9
Male	28	52.3	30.6	71.3	26.3
Age					
65-74	32	53.8	26.5	71.7	24.0
75+	16	50.3	31.5	58.9	31.5
Site					
Br/Co/Pr	10	71.7	28.4	81.0	20.9
Lung	38	47.6	25.9	63.9	27.6
Stage					
Early	13	47.3	30.4	63.9	32.2
Late	35	54.6	27.2	68.7	25.3
Cómorbid					
0-1	15	55.5	27.2	73.2	25.4
2	8	61.2	33.7	77.0	22.2
3+	25	48.2	26.8	60.9	28.7
Interval to De	ath (Da	ays)			
≤ 120	17	49.6	29.7	67.1	29.9
121-240	16	49.2	30.2	67.8	27.4
> 241	15	59.8	23.7	67.3	25.3

<u>SF-36 Physical Function Scores at PF 3M* and Interview Prior</u> to Death by Independent Variables

*PF 3M: SF-36 scores 3 months before diagnosis **SF 36: SF-36 scores at interview prior to death

independent variables identified as statistically significant in the ANOVA model (gender, site, physical function 3 months before diagnosis) at the interview prior to death and at the three month prior to diagnosis point. At the three month point, males (n=28) had higher mean levels of physical function (M=71.3, SD=26.3) compared to female (n=20) scores (M=61.9, SD= 27.9). However, at the interview prior to death, males showed a greater decrease in level of function (m=52.3, SD=30.6) with lower scores than females (m=53.2, SD=24.6) being reported. Lung cancer patients reported lower mean levels of SF-36 physical function scores three months prior to diagnosis (m=63.9, SD=27.6) and at the interview prior to death (m=47.6, SD=25.9) than those patients diagnosed with breast, colon, and prostate cancer (see Table 3).

To interpret Table 3 it is possible to say that 71% of the men (n=28) were able to accomplish the tasks in the SF-36 without limitations three months before diagnosis, but at the interval before death only 53% were able to accomplish the tasks without limitation, a difference of 18%. Three months before diagnosis 62% of the women (n=20) were able to accomplish the tasks in the SF-36 without limitations and 53% reported no limitations at the interval before death, a difference of 9%. It appears within this subsample men reported increased limitations in physical function than women when measured before diagnosis and at the interval before death.

Cross tabulations between the dependent variable physical function, measured by SF 36, IADL and ADL scores, was done in an attempt to demonstrate a relationship between SF-36 physical function scores and increasing levels of dependence reported in IADLs and ADLs. Each independent variable (gender, age, site, stage, comorbidity) was placed

within the model separately to determine the number of patients reporting independence or dependence in IADLs and/or ADLs. These cross tabulations were done to add a descriptive dimension to the sample (see Tables 4, 5, 6, 7, and 8).

The Chi-square test was used to determine the significance of this cross tabulation. The Chi-square test is used with categories of data and hypotheses about the proportions of cases falling into the various categories. However, because of the small sample size (n=57), statistically significant relationships were not observed except with gender (see Table 4). In Table 4 more men report being independent (n=21, 36%) than women (n=3, 5%), more women (n=16, 28%) report dependencies in IADLs not ADLs than men (n=8, 14), and nearly equal numbers report dependencies in both IADLs and ADLs. It seems reasonable to postulate that more women reported dependencies in IADLs than men because the tasks measured in the IADLs are more role specific for women (shopping, laundry, housework and meal preparation). Because 56% of the cells in the cross tabulations have expected counts less than 5 the Chi-square may not be a valid test. Even though the Chi-square result for gender (see Table 4) appears to be statistically significant (p=0.00) there are 3 cells with 5 or fewer numbers out of the total of 6 cells in the table. A similar pattern of low numbers in the cell categories can be seen in Tables 5, 6, 7, and 8.

Table 4.

Numbers and Percent of Patients Reporting Dependencies in IADL and ADL by Gender

Physical Function	Fema	le	Mal	e	Total	
•	n	*	n	\$	n	ł
Independent: IADL and ADL	3	5	21	37	24	42
Dependent:IADL not ADL	16	28	8	14	24	42
Dependent: IADL and ADL	4	7	5	9	9	16
Total	23	40	34	60	57	100
Statistic	DF Valu		ue	Pro	b	
Chi-Square	2		14.	703	.00	

Table 5.

Number and Percent of Patients Reporting Dependencies in IADL and ADL by Age

Physical Function	Age	65-74	Age	75+	Total	
	n	8	n	8	n	*
Independent: IADL & ADL	17	30	7	12	24	42
Dependent: IADL not ADL	17	30	7	12	24	42
Dependent: IADL & ADL	3	5	6	11	9	16
Total	37	65	20	35	57	100
Statistic	DF	Value		Prob		
Chi-Square	2	4.679		.09		

Table 6.

Number and Percent of Patients Reporting Dependencies in IADL and ADL by Site

Physical Function	Br/	Co/Pr	Lun	a	Total	
-	n	` *	n	*	n	¥
Independent: IADL & ADL	6	11	18	32	24	42
Dependent: IADL not ADL	4	7	20	35	24	42
Dependent: IADL & ADL	1	2	8	14	9	16
Total	11	19	46	81	57	100
Statistic	DF	Value		Prob		
Chi-Square	2	0.995		.60		

Table 7.

Number and Percent of Patients Reporting Dependencies in IADL and ADL by Stage

	Ear	ly	La	te	Total	
Column Percent	n	- 8	n	8	n	\$
Independent: IADL & ADL	6	11	17	30	23	41
Dependent: IADL not ADL	7	13	17	30	24	43
Dependent: IADL & ADL	2	4	7	13	9	16
Total	15	27	41	73	56	100
Statistic	DF		Value		Pro	b
Chi-Square (missing freq=1)	2		0.1	71	.92	

Table 8.

Number	and	Percent	of	Patients	Reporting	g Dependenci	<u>ies in</u>
IADL ar	nd AD	L by Cor	or	oidity	_		

Physical	Comorbids	0-1		2		3+		Total	
Function		ກຼ	\$	n	8	n	\$	n	£
Independent	: IADL & ADL	7	13	5	9	11	20	23	41
Dependent:	IADL not ADL	7	13	3	5	14	25	24	43
Dependent:	IADL & ADL	3	5	2	4	4	7	9	16
Total		17	30	10	18	29	52	56	100
Statistic		DF		Value		Pro	b		
Chi-Square (missing fr	eq.=1)	4.	1.075 .		.90				

In Table 5 it can be seen that more younger patients report being independent or have some dependencies in IADL but not ADL (n=17, 30%) than older patients (n=7, 12%), and that fewer younger patients report dependencies in both IADLs and ADLs (n=3, 5%) than older patients (n=6, 11%). However, since younger patients are the majority (n=37, 65%) of the patients in this subsample it would be difficult to draw any definitive conclusions comparing the age groups. It would appear that the majority of the younger patients stay independent in IADLs and ADLs, with few reporting dependencies. In the same respect, it appears that equal numbers of older patients report dependencies in the three categories. I would conclude from Table 5 that while proportionally equal patients in the age groups in this study reported either being independent in IADLs and ADLs or some dependencies in IADLs, it is the older patient who is more apt to become dependent in ADL activities. This is significant in the development of intervention strategies.

In Table 6 the majority of the lung patients (n=38, 67%) report being independent or have dependencies in IADLs only. Similarly, the majority of the breast, colon, and prostate patients report being independent or have dependencies in IADLs only (n=10, 18%) for a total of 48 (85%) of the subsample reporting independence or dependence in IADLs in the interval prior to death. However, 14% of the patients with lung cancer reported dependencies in IADLs and ADLs with only 2% of the patients with breast, colon, and prostate reporting like dependencies. An awareness that lung cancer patients are more likely to be dependent in ADLs is important in the development of appropriate strategies.

Patterns in Table 7 are similar to the majority of the patients (n=13, 24%) in Early stage and Late stage (n=34, 60%) reporting independence or dependence in IADLs alone for a total of 47 (84%) of the respondents. While many late stage cancer patients report independence in IADLs and ADLs or restrictions in IADLs alone, it is the late stage cancer patient who is most likely to be dependent in both IADLs and ADLs.

The majority of the patients reporting comorbid conditions (see Table 8), even those with 3 or more
comorbidities, report being independent or with dependencies in IADLs alone (n=47, 84%). Relationships may be significant with a larger sample size.

Preliminary conclusions drawn from these cross tabulations on this sample size would indicate that the majority of the patients in this study were independent in ADLs leading to the conclusion that the focus of interventions should be toward assisting patients with IADLs regardless of the gender, age, site, stage, or numbers of comorbid conditions. However, it would seem that older (75+) late stage lung cancer patients are the most likely individuals to report dependencies in both IADLs and ADLs regardless of gender or numbers of comorbid conditions. A larger sample size may either confirm or dispute these conclusions. Also, this researcher suspects that there is an interaction effect not measured (treatment modality and/or symptoms experienced) which may prove to be beneficial in explaining differences observed in physical function prior to death.

Table 9 represents a type of sensitivity analysis applied at the time of diagnosis combined with the interview before death with the number of cases of patients reporting dependencies in IADLs and ADLs compared with the SF-36 scaled scores. The purpose of this analysis is to describe at what SF-36 scores patients will begin to report dependencies in IADLs and ADLs. The intent of this is to determine if this model is sensitive in predicting the

Table 9.

Relationship of SF-36 Limitations with IADL and ADL Dependencies Reported by Patients

	SP	-36		IADL D	epedencie	s Waves	1 & 2	ADL	Depende	ncies W	ave 1 &	2
	0	1	2	e	4	s	0	1	2		4	5
SF36	п	u	n	u	n	u	п	a	u	n	u	a
90- 100	7	1	0	1	1	0	10	0	0	0	0	0
80-89	6	0	1	0	0	1	11	0	0	0	0	0
70-79	4	2	0	2	0	0	8	0	0	0	0	0
60-69	5	1	2	2	3	0	13	0	0	0	0	0
50-59	3	0	2	0	0	0	З	0	1	1	0	0
40-49	2	1	0	1	2	0	5	1	0	0	0	0
30-39	3	2	2	3	0	2	8	3	0	0	0	1
20-29	2	2	1	З	2	1	5	5	1	0	0	0
10-19	2	0	2	1	0	0	5	0	0	0	0	0
0-9	3	1	0	0	2	2	2	1	3	0	1	1
Total	40(45%)	10(11%)	10(11%)	13(15%)	10(11%)	6(7%)	70(79%)	10(11%)	5(6%)	1(1%)	1(1%)	2(2%)

levels of physical function of the elderly cancer patients at the time of diagnosis. This information will then be compared to the same model applied at the interview prior to death to determine patterns of physical function and changes in patterns over time. The sample size of used in this table is larger (n=89) because of ongoing analysis in the larger study and only adds to the ability to draw conclusions about the sensitivity of this measure as a predictor of physical function.

Preliminary analysis indicates that the majority of patients, regardless of SF-36, scores remained independent in ADLs (n=70, 79%) and almost half were independent in IADLs (n=40, 45%). An additional 10 (11%) patients described needing supervision only with ADLs to total 80 (90%) of the patients requiring minimal assistance with ADLs. The remainder of the patients reporting dependencies in IADLs were evenly distributed from requiring supervision only to requiring total physical assist (n=10, 11% for both). It would appear that no assumptions can be made about the IADL and ADL scores of a patient from the SF-36 scores which supports the need to use multiple measures of physical function in determining a patients needs for assistance.

In response to research question number 1, site (lung cancer), gender (male), and level of physical function at the time of diagnosis appear to be the independent variables most significant in predicting levels of physical function at the interview prior to death for the 57 participants in this study. It would also appear that although the majority of patients remain independent in ADLs it is important to note that older lung cancer patients with late stage disease are the patients most likely to report dependencies in the ability to perform basic activities of daily living regardless of gender or comorbidities. This is important for the advanced practice nurse to know in planning intervention strategies within systems concerned with allocation of limited resources and the appropriate distribution of these resources.

2) Are there differences in the level of physical function experienced by males and females with lung or colon cancer in the months prior to their death?

Table 3 would suggest that three months prior to diagnosis men (n=28) report higher levels of SF-36 physical function (M=71.3, SD=26.3) than women (n=20, M=61.9, SD=27.9). However, levels of SF-36 physical function reported by these same patients at the interview prior to death demonstrate a larger drop in the level of physical function for men (M=52.3, SD=30.6) compared to women (M=53.2, SD=24.6), a decrease in mean levels of SF-36 for men of 19 points compared to a decrease in mean levels of SF-36 for women of 9 points. However, death appears to be the great equalizer with SF-36 reported scores at the interview prior to death almost equal for both men and women (see Table 3).

As discussed previously, Table 4 would suggest that men (n=21, 371) are more likely than women (n=3, 51) to report independent levels of IADLs and ADLs. Also, women (n=16, 281) are more likely to report levels of dependencies in IADLs, but not ADLs than men (n=8, 141). These differences may be attributable to the measurement of role specific items in the IADLs (laundry, shopping, housework, and meal preparation) which for this cohort are more likely done by women than men. Again, Table 4 also shows that men and women report dependencies IADLs and ADLs in equal number. Because the majority of patients in this study were diagnosed with lung cancer it would have been beneficial to make further distinctions based on gender for IADLs and ADLs for these patients in order to draw definitive conclusions.

In response to research question 2 it would appear that although the SF-36 scores for men and women are similar at death, men report a more noticeable drop in their SF-36 scores from the time they are diagnosed with cancer until they die. Because of the sample size it is not possible to say conclusively that women diagnosed with lung or colon cancer report higher levels of physical function than men with the same diagnosis. Further examination of SF-36 scores of patients with lung and colon cancer may lend more insight into the differences in physical function experienced by men and women with these diagnoses and the significance of that gender difference as a predictor within a risk profile.

Discussion

Sample

In this retrospective study, physical function scores for 57 patients who died after completing Wave I and Wave II interviews were reviewed to identify risk factors which might be used to predict physical function in the period prior to death. Higher numbers of lung cancer patients (n=46) died than breast, colon, and prostate cancers combined (n=11). This is consistent with the literature (Abraham et al., 1996; Houts et al., 1988). Because of the small numbers of patients dying from breast, colon, or prostate cancer in this sample it will be difficult to draw any conclusions about the relationships of age, gender, site, stage and comorbidity as predictors of physical function.

Functional Levels and Gender

It would appear that elderly cancer patients, regardless of gender, have similar low levels of reported SF-36 prior to death indicating that gender has little impact on ones ability to function. The most noticeable gender difference in this study was that men had a greater decrease in SF-36 (19 points) implying the need to continually monitor patients throughout the trajectory of cancer rather than one point in time. This is consistent with the literature (Dudgeon et al., 1995; Kurtz et al., 1994; Houts et al., 1988) which recommend the need of cancer patients to receive a continuum of care as opposed to

addressing needs only at diagnosis or prior to death. Gender as a predictor of physical function is a significant consideration in having an awareness that men may report a greater increase in limitations than women from the time of diagnosis to the time of death, but that at death there is probably no difference in the level of physical function reported.

Functional Levels and Site

Not surprisingly, the majority of the patients who died in this study were in the late stage of cancer $(\underline{n}=41)$, and even more were diagnosed with lung cancer (n=46). The late stage diagnosis along with the large number of patients diagnosed with lung cancer is consistent with at least one study (Given et al., 1994) which reported a short survival rate for lung cancer patients. However, this shortened survival (less than 6 months) made it difficult to draw conclusions about the site of cancer impacting the reported physical function scores. In this study, lung cancer patients reported lower levels of physical function at the time of diagnosis (SF-36=63.9) compared to breast, colon, and prostate patients (SF-36=81.0) and reported lower SF-36 scores prior to death (47.6) than the others (71.7) (see Table 3). In at least one other study (Houts et al., 1988), the unmet needs reported were ADLs in nonwhite, younger, breast cancer patients. No comparable conclusions can be made from this study because of the small sample size (Br/Co/Pr n=11). It would appear that site of cancer (lung)

would be a useful predictor of physical function within a risk profile.

Functional Levels at Diagnosis Compared to the Interview Prior to Death

SF 36 levels of function reported at diagnosis compared to SF 36 levels of function prior to death have not been discussed in the literature. In this study, the level of function reported at diagnosis in all cases was higher (SF-36=67) than the level of function reported at the interview prior to death (SF-36=49) for those dying within 240 days of the interview and those dying more than 241 days of the last interview (SF-36=60) (see Table 3). Most significant changes in level of function occurred, as previously discussed, between males and females. Also, as previously discussed, lung cancer patients had lower levels of function reported at the time of diagnosis and at the interview prior to death than those patients diagnosed with breast, colon, or prostate cancer. However, the specific reasons for these differences remain unclear and deserve closer scrutiny in order to develop appropriate intervention strategies. Possible reasons could include: the number of comorbid conditions present (Satariano, 1993); the late stage at the time of diagnosis (Given et al., 1994); or the advanced age of those diagnosed with lung cancer in addition to comorbid conditions (Yancik et al., 1996) who were recruited into this study, as well as the type of treatment received. Conclusions that could be drawn about interval of time

before death for the patients in this study are that SF-36 physical function scores are the same 6 months before death as they are at 3 months before death. The usefulness of this information is that it would appear the limitations in function reported by the SF-36 score reach a plateau. Further research with the participation of caregivers in the reporting of SF-36 scores for patients at intervals of 30, 60, and 90 days before death might prove beneficial in the development of appropriate interventions. Summary of Statistically Significant Predictors

Within this small sample size it would appear that predictors of physical function include: gender, site of cancer, and level of function at the time of diagnosis. Evidence of this from the data are that male patients and those with lung cancer report larger drops in the levels of physical function from the date of diagnosis until the interview prior to death. A more in-depth look at the gender of those patients in this study who died from lung cancer is suggested. One source in the literature (Sarna, 1994) suggests that women with lung cancer have better survival rates than men, possibly related to better functional status at the time of diagnosis. This researcher suspects there are interaction effects related to other factors (comorbidity, age, stage, interval before death, treatment and symptoms) which might be used as predictors of physical function and that would be more statistically significant with a larger sample size. Sarna (1994)

suggests that the presence of comorbid disease influence physical function, that social factors (gender, financial impact, and social support) have been linked to greater unmet needs, and that differences in previous levels of function may be relevant in determining the level of satisfaction rather than functional status. Clearly, other factors deserve closer scrutiny in determining the full range of factors impacting physical function in the terminally ill elderly cancer patient.

Functional Levels Related to Age, Stage, Interval Before Death. Comorbidites

Although age, stage, interval before death, and number of comorbidities were not statistically significant as predictors of physical function prior to death, the change that occurs in level of SF-36 physical function from the time of diagnosis to the interview prior to death deserves attention. It is this change in physical function that patients may be most aware of and which may contribute to feelings about their diagnosis and participation in treatment. An awareness on the part of health care providers about this change in physical function can facilitate the development of interventions proactively. Gender differences and site differences in levels of reported SF-36 function have already been discussed. Other differences noted will be discussed at this time.

Functional Levels and Age

Younger patients (those aged 65-74) report higher mean levels of SF-36 physical function (M=71.7, SD=24.0) compared to older patients (those aged 75+) SF-36 physical function scores (M=58.9, SD= 31.5) at the time of diagnosis in this study (see Table 3). SF-36 physical function scores reported at the interview prior to death for both age groups were similar (age 65-74, M=53.8, SD=26.5; age 75+, M=50.3, <u>SD</u>=31.5), with a more significant change over time in the two scores for younger than older patients. The relationship of this change to site of cancer cannot be determined from this data. However, it is worth noting that the oldest patients are already functioning at compromised levels at the time of diagnosis and may have less noticeable increases in limitations or dependencies. Lower levels of SF-36 physical function would suggest some limitations in ability to perform IADL activities in the older patients at the time of diagnosis. Table 9 supports the need to access physical function with the use of multiple tools to determine physical function and help to determine differences related to age. The determination of this correlation in the development of appropriate intervention strategies is important. The literature (Whittle & Goldenburg, 1996) supports this contention because the successful performance of IADL activities is fundamental in maintaining noninstitutionalized, independent living arrangements for the elderly. It would seem reasonable to

assume that understanding this relationship between independence and dependency could lead to the development of nursing interventions that would support adaptations in physical function to maintain independent living for as long as possible in end of life. It would appear that these interventions would be most appropriate for the younger-old because of their higher SF-36 physical function scores at the time of diagnosis.

Functional Level and Stage

Within this study, SF-36 physical function scores for early (<u>M</u>=63.9, <u>SD</u>=32.2) and late (<u>M</u>=68.7, <u>SD</u>=25.3) stage cancers were similar except that those with early stage cancer had slightly lower scores than late stage cancer patients. Early stage cancer patients (n=13) reported a slightly larger drop in levels of physical function (16.6 points) compared to late stage cancer patients (n=38,14.1 points). Because the sample sizes are dissimilar and the difference is small this may not be a significant observation. A larger sampling might give some insight into reasons for the difference. Explanations might include the possibility that: patients with early stage cancer had more comorbid conditions and therefore lower levels of physical function; patients diagnosed with early stage cancer were receiving more aggressive treatment modalities impacting their functional abilities; or, age and gender may be factors influencing the level of physical function in those individuals diagnosed with early stage cancer. It might be

useful to know the site of cancer for these early stage patients and to know the rapidity of the decline in physical function they experienced. Before conclusions can be drawn about the impact of stage on physical function a larger sample size needs to be evaluated. Treatment modalities and symptoms experienced for patients within both stage categories may give some insight into the differences in physical function experienced. Questions to answer include: are the early stage cancer patients receiving more aggressive treatment modalities and are they experiencing a more rapid decline in physical function than late stage cancer patients.

Functional Level and Comorbidity

Within this study, patients with at least 2 or more comorbid conditions accounted for the majority (n=39, 70%) of the patients reporting comorbidity. This is consistent with the literature (Yancik et al., 1996; Sarna, 1994) which reports higher numbers of comorbid conditions reported with advancing age. Other studies have demonstrated increased service utilization for patients with higher numbers of comorbid conditions (Blaum et al., 1994). Although this researcher did not specifically look at service utilization as a covariate it would seem reasonable to conclude that patients with higher numbers of comorbid conditions and service utilization would also have need for more assistance with physical function.

One study reported that women diagnosed with breast cancer who had 2 or more comorbidities were more likely to die from their breast cancer (Satariano, 1993). Although few breast cancer patients were available in this study, the majority of patients dying reported 2 or more comorbid conditions. This suggests that the cause of death for these patients is specifically related to the cancer diagnosis, specifically related to the comorbid condition, an exacerbation of the comorbid condition related to the treatment modality, or failed treatment related to the comorbid condition. While specific facts for breast cancer patients are not available in this study, comorbidity appears to have a similar impact as the Satariano (1993) study and should be considered in future work to determine the specific relationship of comorbidity to death and as a predictor of physical function in the period prior to death. Functional Levels and Interval Before Death

SF-36 physical function scores in this sample were identical (M=67.1, SD=25.3 to 29.9) when measured at the time of diagnosis for all three levels of intervals measured (see Table 4). SF-36 physical function scores were also identical at the interview prior to death for patients who died \leq 120 days (M=49.6, SD=29.7) and those who died 121-240 days (M=49.2, SD=30.2) after their last interview. Slightly higher levels of SF-36 physical function (M=59.8, SD=23.7) were reported by those patients who died \geq 241 days after the last interview and would be expected to be higher

considering the length of time until death. The usefulness of the interval before death as a predictor of physical function within this sample size is limited with apparently no differences in reported levels of physical function at the three intervals of time.

In summary, it would appear that gender (men), site of cancer (lung) and level of physical function at the time of diagnosis are statistically significant predictors of physical function for elderly terminally ill cancer patients. What we don't know is how treatment modalities and symptoms experienced as a result of treatment (or lack of treatment) impact the physical function of a patient prior to death or if the treatment or symptoms contribute to limitations in physical function. Because of the small sample size generalizing to a larger population should be done with caution.

Discussion of Results within the Conceptual Framework

The results of this study support the adapted Predictor of Physical Function Model framework in that gender, site of cancer, and prior level of function were shown to be statistically important predictors of SF-36 physical function. However, a better representation of the relationship of the three measurements of physical function would be demonstrated through the use of a Venn diagram. In this manner the SF-36, IADL and ADL scores could be represented as separate and distinct (to show their unique characteristics) and overlapping (to demonstrate their similarities) (see Figure 3).

Tables 9 refutes the demonstration of a relationship of the SF-36, IADLs, and ADLs within the four categories proposed. That is, as SF-36 scores decrease predictions can be made about limitations in IADLs and ADLs. It is suggested that the revised model and statistical techniques be applied to a larger sample size with the inclusion of treatment modalities and symptoms as covariates. In this way, interaction effects can better be determined and a possible valuable risk factor tool can be developed to assist the advanced practice nurse in developing appropriate strategies for the elderly terminally ill cancer patient. Implications for Advanced Practice Nurses

By the year 2030 it has been estimated that those over the age of 65 will represent 15-18% (Whittle & Goldenberg, 1996) or as high as 21% of the population. Health care services previously provided within acute care settings are increasingly becoming the responsibility of patients and their caregivers in home care settings. It has also been shown that it is the loss of physical function which is a primary factor in forcing institutionalization of elderly individuals. For the elderly population it has been suggested that nursing interventions to prevent institutionalization must promote and support functional adaptation methods (Whittle & Goldenberg, 1996). The advanced practice nurse is in a unique position to assist

75 CONCEPTUAL MODEL (revised) An adaptation of the Family Care Process Model by Given and given



Figure 3. Predictors of Physical Function Model (Revised).

the terminally ill elderly cancer patient and family caregivers in the development of appropriate strategies that promote function and maintain quality of life. Knowledge of predictors of physical function within this population will assist the advanced practice nurse to develop these strategies and interventions.

The advanced practice nurse will be expected to assume greater responsibility in the managed care setting to provide cost effective, competent care. For the geriatric population new models of delivery management might include brokerage (with assessment, planning, and packaging of community resources) or waiver programs to purchase needed services (Strumpf & Paier, 1993). As part of these models the advanced practice nurse will be expected to accurately assess the needs of a given patient. Predictors of physical function in the form of a risk factor profile for the elderly terminally ill cancer patient will assist the advanced practice nurse in the assessment process.

Based on findings from this study, a risk factor profile could be developed to assist the advanced practice nurse in the development and implementation of strategies. Factors to include in the risk factor profile would be gender, site, physical function scores at the time of diagnosis as well as stage and comorbidities. From this study, advanced practice nurse should be able to conclude that any patient with late stage lung cancer who is 75 years old or older will be dependent in ADLs. Other conclusions that may be helpful in determining the needs of a patient are that men notice a greater decline in SF-36 function and that lung cancer patients start out with lower levels of function and have lower levels of function prior to death than patients with breast, colon, and prostate cancer. This knowledge will require the preparation of caregivers to either learn to provide the care themselves, to assist the caregiver and patient in making decisions about home care services or to determine the need for nursing home placement. Most significantly, the advanced practice nurse must be aware that single measurements of physical function

may give incomplete information about an individuals abilities or needs. Instead, the use of the SF-36, IADLs and ADLs will give a multidimensional assessment of physical function related to basic needs (ADLs), needs with gender specific differences (IADLs), and quality of life components (SF-36).

The counseling of patients at the time of diagnosis would appropriately include information regarding expected declines in function and suggestions for adaptation strategies if the patients wish to remain home. Women are more likely than men to require assistance with IADLs that will require adaptation strategies for not only the women but for their male caregivers who might be ill prepared to assume some of the IADL tasks.

Advanced practice nurses should be ready to assess and diagnose the physical function needs of the elderly terminally ill cancer patient. Advanced practice nurses must have an awareness of services provided at referral agencies and make appropriate referrals when necessary. Advanced practice nurses must also be able to determine when the needs of the patient are no longer being met by the caregiver at home by providing a continuum of care that includes intermittent determinations of SF-36, IADL and ADL physical function.

The ability of the advanced practice nurse to predict physical function in the terminally ill elderly cancer patient will promote the development of planning strategies.

Planning strategies derived from appropriate assessments will ensure that appropriate referrals are made to maintain function and quality of life in the end of life. Planning strategies will benefit family caregivers who may be faced with making difficult choices. The ability to predict levels of function will allow the planning and implementation of interventions in a proactive rather than reactive manner.

The advanced practice nurse is uniquely positioned to use the predictors of physical function for the terminally ill elderly cancer patient in a health promotion context. This can best be accomplished by differentiating normal age changes from disease processes impacting physical function. Patients and family members can then be educated about skills that will promote health related to normal changes in aging versus adaptations necessary because of the cancer itself. Some examples of normal changes with aging which may be misinterpreted as declines in physical function from the cancer include loss of visual acuity or hearing deficiencies. Both of these changes may make the elderly person feel less able to move about or participate in activities as they had before and be totally unrelated to their cancer diagnosis. The appropriate strategies for the advanced practice nurse would be to assess for cataracts, presbyopia or presbycusis and provide the appropriate education and referrals. The advanced practice nurse should provide the patient with a thorough physical exam to

determine any physical changes associated with aging and suggest appropriate interventions.

Perhaps the most significant use of predictors of physical function by the advanced practice nurse will be as a patient advocate in assisting the patient to obtain treatment choices in end of life care. Three possible goals of care have been identified for treating those diagnosed with cancer. Included in these goals are curing the disease, increasing survival time, and improving quality of life for terminally ill cancer patients (Greisinger et al., 1997). Terminally ill patients who were interviewed in the study by Greisinger et al. (1997) were able to identify their most highly rated concerns. Included were existential, spiritual, family, physical, and emotional concerns. The researchers were able to identify specific needs and make appropriate referrals after the interviews were complete. In the same manner, an advanced practice nurse who is equipped with knowledge that predicts physical function will be able to discern the patients most important interests related to physical function. The advanced practice nurse can then advocate for palliative care the patient deems most appropriate based on presented information.

By using a risk factor profile that predicts physical function the nurse can provide education materials or information to the patient and family. Preliminary suggestions for a risk factor profile would include the

assessment of SF-36, IADLs and ADLs, the cancer diagnosis, and stage, the patients age and gender, the number of comorbidities, the treatment choices and symptoms experienced as well as the living arrangements, marital status and community services available. A scoring system could be developed, the profile could be administered throughout the course of care with the intend of identifying those at risk for highest needs in relation to physical function. If the nurse tests the patients level of function at the time of diagnosis, potential areas of concern requiring further information related to physical function can be determined. In following the Predictor of Physical Function Model the advanced practice nurse might only have time to administer the SF-36 tool to then be able to draw conclusions about a persons ability to engage in IADL and ADL activities based on the SF-36 score. Someone who describes limitations in ability to climb one flight of stairs may not be able to do the laundry if the equipment is in the basement, but they would be able to if the washer/dryer were on the main floor. Someone who is limited in their ability to bend, kneel, or stoop may not be able to get out of bed. A person who describes limitations in the ability to walk one block may not be able to shop for themselves. Clearly, these examples indicate areas that require education for both the patient and family to maintain daily living needs.

The advanced practice nurse must also be able to make appropriate referrals to other services, a task which could be enabled through the use of a model predicting the physical function of the terminally ill elderly cancer patient. This is especially important if the patient and caregiver want the patient to remain in the home setting in the end of life. Based on this study the patients most likely to require referrals are older, late stage lung cancer patients, male patients, or female patients for IADL assistance. Service referrals might be appropriately made to obtain meals, chore services, assistance with personal care, and respite care for the caregiver. Within the context of limited health care budgets referrals that are suitable may ultimately save the patient and caregivers limited monies.

The advanced practice nurse can effectively function in the role of case manager through the use of a variety of tools. Predicting the level of function in a terminally ill elderly cancer patient, especially older lung cancer patients, and conveying the information to other health care providers in a collaborative manner may assist them in allocating services. It may be up to the advanced practice nurse to decide that the appropriate care for the patient can no longer be provided at home, convey this information to the primary care physician, and collaborate with agencies to appropriately seek placement of the patient.

The role of the advanced practice nurse it the development of health policies cannot be understated. Knowledge of physical function needs of the elderly terminally ill cancer patient will allow the nurse to make appropriate recommendations to congress persons, senators and support current legislation. Hand in hand in the role of the advanced practice nurse as a policy maker is the role of the advanced practice nurse as a researcher. Understanding the needs of a patient population through research based knowledge can only assist the nurse in developing interventions specific to individual needs.

A holistic approach to health care makes it imperative that the advanced practice nurse take into consideration all aspects of the patient in developing care interventions. The Predictor of Physical Function Model takes into consideration features of the patient that may impact their ability to perform including age, gender, site of cancer, stage of cancer, comorbidity, and prior level of function. The value of predicting the physical function of the elderly terminally ill cancer patient lies not only in providing adequate care to the patient, but in assisting the caregiver to manage during a difficult time, and in the allocation of limited health care services.

Implications for Further Research

Because of the small sample size ($\underline{n}=57$) the development of a risk factor profile as predictors of physical functioning in the terminally ill cancer patient is limited.

However, opportunities for further research remain. The literature review reveals limited information about the physical functioning of terminally ill elderly cancer patients. Therefore, suggestions for further research include:

- a) Extended research using the same model (revised) and statistical techniques in a larger patient population from the same data base, and observe changes over time. Incorporating all patients who have died during the entire study may reveal more statistical significance in all covariates. It may also provide a larger percentage of patients dying from breast, colon, or prostate cancer to see if the covariate factors significantly impacting their physical function levels are different than those for lung cancer patients.
- b) The inclusion of <u>symptom experience</u> as a covariate in the equation to determine the impact of the symptoms on the physical function of the individuals involved. This would add important depth in the development of strategies to assist the patients and families in making end of life treatment decisions and choices.
- c) A study that includes <u>treatment modality</u> as a covariate including the place within the treatment cycle, the aggressiveness of the treatment and the impact on physical function. This too would

influence the development and implementation of nursing interventions and end of life choices made by patients and families.

- d) A study that addresses physical function specifically as a quality of life issue with implications for treatment choices including palliative care as a treatment choice and complications of treatment impacting physical function. Looking at the congruence of patient choices and caregiver choices should be included.
- e) Further study of the relevance of prior level of physical function to the level of function prior to death. It would be interesting to note if people with limitations at the time of diagnosis of cancer related to other comorbid conditions have already adapted to the limitations and therefore have higher physical function scores prior to death.
- f) The relationship of comorbid conditions to the physical functioning of the terminally ill elderly cancer patients more specifically defined. For example, it would be interesting to know if patients with comorbid conditions such as heart disease and hypertension have higher, lower, or similar levels of physical function than those with pulmonary or neurological comorbidities. This information would add another dimension to the risk factor profile and provide the advanced practice

nurse with even greater knowledge about suitable interventions.

- q) A study about the caregivers needs of patients with limited physical function and the benefit to them of using a risk factor profile predicting physical function. While it may be useful for the nurse to implement interventions, outcomes of care that benefit the caregiver and patient will be most useful. The study should include: cost savings for the caregiver, patient, and health care system; decreased reporting of stress and anxiety for the caregiver; and, increased reported levels of satisfaction for bother the caregivers and the patient. I would support the development of a risk factor profile that provides the patient and caregiver with information that they can use to determine the care most appropriate to meet the needs of their value system.
- h) A study that addresses more efficient service utilization for those patients who have been evaluated using a risk factor profile for physical function in the end of life. This is another measurement of the outcome of care provided by the advanced practice nurse.
- A study of the concepts of sick roles and disability specifically with older men with late stage cancer compared to older women with late

stage cancer to determine if there indeed is sick role behavior which could be used as a predictor of physical function.

Increasing research based knowledge will add credibility to the decisions that will allow the advanced practice nurse to deliver cost effective care is imperative in today's changing health care market. Patients and families are becoming more knowledgeable and informed about their choices in care. It is important that advanced practice nurses who are assuming primary care positions provide services that are not only appropriate, but based on sound, nursing research.

Summary

Clearly, a key role of the advanced practice nurse related to physical function in the care of the elderly terminally ill cancer patient is that of the assessor. The advanced practice nurse is in a unique position to utilize tools such as the SF-36, IADLs and ADLs in conjunction with advanced knowledge and cues obtained from the patient to develop appropriate strategies of care. The relationship between end-of-life care and quality of life issues as they relate to physical function for the geriatric cancer patient must be examined. The potential incongruent perception between what the health care system is willing to provide and what the elderly desire in the end-of-life must be identified through research. This study focused on predictors of physical function in the terminally ill

elderly cancer patient. Independent variables that proved to be statistically significant included site of cancer, gender, and prior level of function.

A model was presented that would demonstrate the relationship of the independent variables (age, gender, site, stage, comorbidity, and prior level of function) to the dependent variable physical function measured using the SF-36, IADLs and ADLs. It was proposed that four categories of physical function could be developed and that patients could be placed in one of these categories based on their levels of reported function. Unfortunately, because of the small sample size it was not possible to show statistical significance by Chi-Square for cross-tabulations run on the covariates with the dependent variable. Clearly, there was not a relationship of progression in physical function from independence to dependence that can be predicted through the use of the four proposed categories.

It does appear that in this sample male patients are more likely to report greater decreases in levels of physical function than female patients when measured at the time of diagnosis and the interview prior to death. Lung cancer patients, male or female, appear to have lower levels of physical function at both measurement intervals. The most important finding from this is the value of measuring physical function at the time of diagnosis in the development of appropriate strategies. This certainly should become a standard of practice in each and every

oncology office. Without this information it is impossible to draw any conclusions about the specific needs of individuals.

Certainly, the needs of the elderly will increase as the cohort lives longer and grows larger in number. It is essential that current researchers study the needs of this population of people to provide the most appropriate care possible. The trend for elderly to make end of life choices such as physician assisted suicide make it imperative that health care providers identify and address the needs of these individuals, providing them with more choices. Quality of life must become a priority in the delivery of care to people who are nearing the end of their life. No longer can we afford to be complacent in the delivery of care as we race toward the millennium. The demand for changes in health care place the burden of change on providers of care. Advanced practice nurses accustomed to providing compassionate care must assume a lead role in the delivery of research based, collaborative care to a changing marketplace.

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APPENDIX A

Instruments

Comorbities

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ID ____/INT ___ Date __/__/___

PHYSICAL HEALTH PATIENT

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

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

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

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

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

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

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

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

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

8a. Have you had any of these problems in the last 12 months? (check one)

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

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

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

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

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

11. Do you have any other major health problems which you haven't told me about? (check one)

____Yes (Go to 11a) (1) ____No (Go to Next section) (2) ____DK/NA/Refused (9)

11a. If yes, what are they? (write in)

SF-36

Physical Function

INSTRUMENTAL ACTIVITIES OF DAILY LIVING FOR THE PATIENT

 The following questions are about the activities you might do during a typical day. I am going to ask you about your ability to perform these activities currently. Does your health limit your ability to do activities? If so, how much? (Check one for each question.)

(Interviewer: Are you currently limited in ... because of your health? We are interested in your ability to do these activities.)

- a. <u>Hoderate activities</u>, such as moving a table, bowling, or playing golf?
 - No, not limited at all (1)
 - Yes, limited a little (2)
 - Yes. limited a lot (3)
- b. <u>Vigorous activities</u>, such as lifting heavy objects or participating in strenuous sports?
 - No, not limited at all (1)
 - Yes, limited a little (2)
 - Yes, limited a lot (3)
- c. Lifting or carrying groceries?
 - No. not limited at all (1) Yes, limited a little (2) Yes, limited a lot (3)
- d. Climbing several flights of stairs?
 - No, not limited at all (1) Yes, limited a little (2) Yes, limited a lot (3)
- e. Climbing one flight of stairs?
 - No. not limited at all (1) Yes, limited a little (2) Yes, limited a lot (3).
- f. Bending, kneeling, or stooping?
 - No. not limited at all (1) Yes. limited a little (2)
 - Yes. limited a lot (3)

g. Walking one block?

No. not limited at all (1)
Yes, limited a little (2)
Yes, limited a lot (3)

h. Walking several blocks?

No. not limited at all (1)
Yes. limited a little (2)
Yes. limited a lot (3)

i. Walking more than a mile?

No. not limited at all (1) Yes. limited a little (2) Yes. limited a lot (3)

j. Bathing or dressing yourself?

No. not limited at all (1) Yes, limited a little (2) Yes, limited a lot (3)

2. How much overall physical pain have you had during the past four weeks? (check one)

- None (1) Very Mild (2) Mild (3) Moderate (4) Severe (5) Very Severe (6)
- 3. During the past four weeks, how much did pain interfere with your normal work (including both work outside the home and housework)? (check one)
 - Not at All (1)
 Slightly (2)
 Moderately (3)
 Quite a Bit (4)
 Extremely (5)

(GO TO NEXT PAGE)

ID _____/INT ____ Date ___/___/___

IADLs

ID ____/INT ___

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

7) TRANSPORTATION

- 7a. With regard to getting to places outside of walking distance, i.e., going to the doctor's or grocery shopping away from your neighborhood ... (check one)
 - ____ DRIVE SELF (do not need help of another person in any part of this activity) (Go to question 7) (1)
 - MEED SUPERVISION ONLY (require another person present during activity to watch the patient in case of problems - do not regularly assist) (Go to 6b) (2)
 - MEED SOME PHYSICAL HELP (require others to drive and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATES (Go to 6b) (3)
 - ____ NEED TOTAL PHYSICAL HELP (need another person to drive)
 - CARE RECIPIENT DOES NOT PARTICIPATE (Go to 6b) (4)
 - ____ NOT APPLICABLE (others have always done this) (Go to 7) (5)
 - _____ NA/REFUSED (9)

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7b. Is the reason for this help related to your (cl	heck one)
<pre>Cancer or cancer treatment (Go to 7c) (1) Concer health problem(s) (Go to 7c) (2) NA/Refused (9)</pre>	
7c. If someone helps you with transportation (check	(all that apply)
<pre> primary caregiver (1) (Go to 7d) unpa paid family (2) (Go to 7f) unpa paid friends/others (3) (Go to 7f) unpa paid professional (4) (Go to 7f) NA/R</pre>	id family (5) (Go to 7e) id friends/others (6) (Go to 7e) id professional (7) (Go to 7e) efused (9)
7d. If the primary caregiver helps with transportation .	
 In the past week, how many times did he/she (write in) 	help with transportation?
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.)

- 7e. If other unpaid helpers (family, friends, or professionals) help with transportation ...
 - In the past week, how many times did these unpaid others help with (1) 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.)

ID - -- -DATE

- 7f. If other paid helpers (family, friends, or professionals) help with transportation ...
 - 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. With regard to laundry, would you say that you ... (check one)

- ____ ARE INDEPENDENT (do not need help of another person in any part of this activity) (Go to question 9) (1)
- NEED SUPERVISION ONLY (require another person present during activity to watch the patient in case of problems - do not regularly assist) (Go to 8b) (2)
- _____ NEED SOME PHYSICAL HELP (require physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATES (Go to 8b) (3)
- ____ NEED TOTAL PHYSICAL HELP (need another person to carry out this activity) CARE RECIPIENT DOES NOT PARTICIPATE (Go to 8b) (4)
- OTHERS HAVE ALWAYS DONE THIS (Go to 8b) (5)
- NA/REFUSED (9)

8b. Is the reason for this help related to your ... (check one)

- Cancer or cancer treatment (Go to 8c) (1)
- Other health problem(s) (Go to 8c) (2)
- ____ NA/Refused (9)

NINR/NCI WAVE II PATIENT W/O CAREGIVER TELEPHONE ID _____/INT ___ Date ___/___/ 8c. If someone helps you with laundry ... (check all that apply) ____ unpaid family (5) (Go to 8e) primary caregiver (1) (Go to 8d) ____ paid family (2) (Go to 8f) ____ unpaid friends/others (6) (Go to 8e) _____ paid friends/others (3) (Go to 8f) _____ unpaid professional (7) (Go to 8e) ____ paid professional (4) (Go to 8f) ____ NA/Refused (9) 8d. If 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.) 8e. 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.) 8f. If other paid helpers (family, friends, or professionals) help with laundry (1) In the past week, how many times did these paid others help with laundry? (write in) _____ Times per week (2) Approximately how long in minutes each time did these paid others help with laundry? (write in) _____ Minutes each time

1

ID____/INT___ Date___/__/___

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

9) SHOPPING: Includes all types of purchases.

9a. With regard to shopping, would you say that you ... (check one)

- _____ ARE INDEPENDENT (do not need help of another person in any part of this activity) (Go to question 10) (1)
- _____ NEED SUPERVISION ONLY (require another person present during activity to watch the patient in case of problems do not regularly assist) (Go to 9b) (2)
- _____ NEED SOME PHYSICAL HELP (require physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATES (Go to 9b) (3)
- NEED TOTAL PHYSICAL HELP (need another person to carry out this activity) CARE RECIPIENT DOES NOT PARTICIPATE (Go to 9b) (4)
- OTHERS HAVE ALWAYS DONE THIS (Go to 9b) (5)
 - NA/REFUSED (9)

9b. Is the reason for this help related to your ... (check one)

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

9c. If someone helps you with shopping \dots (check all that apply)

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

9d. 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

ID____/INT___ DATE___/__/

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

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

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

_____ Times per week

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

_____ Minutes each time

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

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

 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.)

(GO TO NEXT PAGE)

- 10) HOUSEWORK: This includes picking up, dusting, light cleaning, vacuuming, or doing dishes.
 - 10a. With regard to housework, would you say that you ... (check one)
 - ____ ARE INDEPENDENT (do not need help of another person in any part of this activity) (Go to question 11) (1)
 - ____ NEED SUPERVISION ONLY (require another person present during activity to watch the patient in case of problems - do not regularly assist) (Go to 10b) (2)
 - NEED SOME PHYSICAL HELP (require physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATES (Go to 10b) (3)
 - NEED TOTAL PHYSICAL HELP (need another person to carry out this activity) CARE RECIPIENT DOES NOT PARTICIPATE (Go to 10b) (4)
 - OTHERS HAVE ALWAYS DONE THIS (Go to 10b) (5)
 - NA/REFUSED (9)
- 10b. Is the reason for this help related to your ... (check one)
 - Cancer or cancer treatment (Go to 10c) (1)
 - Other health problem(s) (Go to 10c) (2)
 - NA/Refused (9)

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

- ____ unpaid family (5) (Go to 10e) ____ primary caregiver (1) (Go to 10d)
- ____ paid family (2) (Go to 10f)
- _____ unpaid friends/others (6) (Go to 10e) ____ paid friends/others (3) (Go to 10f) ____ unpaid professional (7) (Go to 10e)
- ____ paid professional (4) (Go to 10f) _ NA/Refused (9)
- 10d. If the primary caregiver helps with housework ...
 - In the past week, how many times did he/she help with housework? (write in) (1)

_____ Times per week

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

_____ Minutes each time

ID _____/INT ___ Date ___/___/___

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

10e. If other unpaid helpers (family, friends, or professionals) help with housework ...

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

_____ Times per week

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

_____ Ninutes each time

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

10f. 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.)

(GO TO NEXT PAGE)

ID____/INT___ Date___/__/

11) COOKING AND PREPARING MEALS

- 11a. With regard to cooking and preparing meals, would you say that you ... (check one)
 - _____ ARE INDEPENDENT (do not need help of another person in any part of this activity) (Go to Next section) (1)
 - _____NEED SUPERVISION ONLY (require another person present during activity to watch the patient in case of problems - do not regularly assist) (Go to 11b) (2)
 - ______ NEED SOME PHYSICAL HELP (require physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATES (Go to 11b) (3)
 - _____NEED TOTAL PHYSICAL HELP (need another person to carry out this activity) CARE RECIPIENT DOES NOT PARTICIPATE (Go to 11b) (4)
 - OTHERS HAVE ALWAYS DONE THIS (Go to 11b) (5)
 - NOT APPLICABLE (have tube feedings, IV's ONLY) (Go to Next section) (6)
 - NA/REFUSED (9)

11b. Is the reason for this help related to your ... (check one)

- ____ Cancer or cancer treatment (Go to 11c) (1)
- Other health problem(s) (Go to 11c) (2)

_____ NA/Refused (9)

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

- ____ primary caregiver (1) (Go to 11d) ____ unpaid family (5) (Go to 11e)
 ____ paid family (2) (Go to 11f) ____ unpaid friends/others (6) (Go to 11e)
- ____ paid friends/others (3) (Go to 11f) ____ unpaid professional (7) (Go to 11e)
- ____ paid professional (4) (Go to 11f) ____
- ____ NA/Refused (9)
- 11d. If the primary caregiver helps with cooking and preparing meals ...
 - 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

ID _____ Date ____ -__/INT -

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

- 11e. 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.)

- 11f. If other paid helpers (family, friends, or professionals) help with cooking and preparing meals ...
 - (1) In the past week, how many times did these paid others help with cooking and preparing meals? (write in)

_____ Times per week

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

_____ Minutes each time

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

(GO TO NEXT SECTION)

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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.

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

 DRESSING: This category includes the entire process of dressing or being clothed, including change <u>from</u> bed clothing into the set of clothing worn during the day, and change to bed clothing at night. This category DDES NOT include management of clothing during toileting. <u>If you wear bed clothing during the day</u>, answer <u>"NEVER DRESS</u>." Select the category that best describes your level of functioning for DRESSING.

ID ____/INT ___ Date __/__/

- 1a. With regard to dressing, would you say you ... (check one)
 - _____ARE INDEPENDENT (do not need help of another person in any part of this activity) (Go to question 2) (1)
 - _____NEED SUPERVISION ONLY (requires another person present during activity to watch the patient in case of problems do not regularly assist) (Go to 1b) (2)
 - ____NEED SOME PHYSICAL HELP (require physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATES (Go to 1b) (3)
 - NEED TOTAL PHYSICAL HELP (need another person to carry out this activity) CARE RECIPIENT DOES NOT PARTICIPATE (Go to 1b) (4)
 - ARE NEVER DRESSED (Go to 2) (5)
 - NA/REFUSED (9)

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

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

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

 primary caregiver (1) (Go to 1d)	 unpaid family (5) (Go to 1e)
 paid family (2) (Go to 1f)	 unpaid friends/others (6) (Go to 1e)
paid friends/others (3) (Go to 1f)	unpaid professional (7) (Go to 1e)

- _____ paid professional (4) (Go to 1f) _____ NA/Refused (9)
- 1d. If the primary caregiver helps with dressing ...
 - 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.)

____/INT ___ ID DATE

- 1e. 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.)

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

_____ Times per week

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

_____ Ninutes 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. With regard to eating, would you say you ... (check one)
 - ____ARE INDEPENDENT (do not need help of another person in any part of this activity) (Go to question 3) (1)
 - ____NEED SUPERVISION ONLY (requires another person present during activity to watch the patient in case of problems do not regularly assist) (Go to 2b) (2)
 - NEED SOME PHYSICAL HELP (require physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATES (Go to 2b) (3)
 - NEED TOTAL PHYSICAL HELP (need another person to carry out this activity) CARE RECIPIENT DOES NOT PARTICIPATE (Go to 2b) (4)
 - ____NOT APPLICABLE (need tube feedings, IV's ONLY) (Go to 3) (5)
 - NA/REFUSED (9)

2d. 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.)

2e. 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.)

2f. 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

ID _____/INT ____ DATE ___/__/___

(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. With regard to bathing, would you say that you ... (check one)
 - ____ ARE INDEPENDENT (do not need help of another person in any part of this activity) (Go to question 4) (1)
 - _____ NEED SUPERVISION ONLY (require another person present during activity to watch the patient in case of problems do not regularly assist) (Go to 3b) (2)
 - NEED SOME PHYSICAL HELP (require physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATES (Go to 3b) (3)
 - _____NEED TOTAL PHYSICAL HELP (need another person to carry out this activity) CARE RECIPIENT DOES NOT PARTICIPATE (Go to 3b) (4)
 - NA/REFUSED (9)

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

 Cancer	or '	can	cer	treatme	nt 👘	(Go	to	3c)	(1)
 Other	heal	th	prot	olem(s)	(Go	to	3c)	(2))
 NA/Re1	lused	1 (9)						

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

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

(GO TO NEXT PAGE)

ID____/INT___

3d. 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) _______ Ninutes each time

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

- 3e. 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.)

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

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

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.

ID _____/INT ___ Date ___/___/___

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- 4a. With regard to walking inside the house, would you say that you ... (check one)
 - _____ ARE INDEPENDENT (do not need help of another person in any part of this activity) (Go to question 5) (1)
 - _____ NEED SUPERVISION ONLY (require another person present during activity to watch the patient in case of problems do not regularly assist) (Go to 4b) (2)
 - _____ NEED SOME PHYSICAL HELP (require physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATES (Go to 4b) (3)
 - _____NEED TOTAL PHYSICAL HELP (need another person to carry out this activity) CARE RECIPIENT DOES NOT PARTICIPATE (Go to 4b) (4)
 - ARE UNABLE TO WALK (will not bear weight) (Go to 5) (5)
 - _____ NA/REFUSED (9)

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

- Cancer or cancer treatment (Go to 4c) (1)
- Other health problem(s) (Go to 4c) (2)
- NA/Refused (9)
- 4c. If someone helps you with walking inside the house, who helps ... (check all that apply)

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

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

 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.)

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ID _____/INT ___ DATE ___/___/

.

- 4e. 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.)

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

(GO TO NEXT PAGE)

ID _____/INT ___ DATE ___/__/___/

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

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

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

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

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

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

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

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

_____ Times per week

ID _____/INT ___ DATE ___/___/___

(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.)

5e. 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.)

5f. 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, tochair or wheelchair. Devices, bars, and other mechanical aids may be used. Select the response that best describes your level of independence.

(GO TO NEXT PAGE)

ID____/INT___

. .

- 6a. With regard to transferring in and out of bed, would you say that you ... (check one)
 - _____ ARE INDEPENDENT (do not need help of another person in any part of this activity) (Go to question 7) (1)
 - NEED SUPERVISION ONLY (require another person present during activity to watch the patient in case of problems - do not regularly assist) (Go to 6b) (2)
 - _____ NEED SOME PHYSICAL HELP (require physical help and the presence of another during all or part of this activity) CARE RECIPIENT PARTICIPATES (Go to 6b) (3)
 - _____ NEED TOTAL PHYSICAL HELP (need another person to carry out this activity) CARE RECIPIENT DOES NOT PARTICIPATE (Go to 6b) (4)
 - REMAIN BEDFAST (Go to 7) (5)
 - NA/REFUSED (9)

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

- Cancer or cancer treatment (Go to 6c) (1)
- Other health problem(s) (Go to 6c) (2)
- NA/Refused (9)
- 6c. If someone helps you with transferring in and out of bed, who helps ... (check all that apply)
 - ____ primary caregiver (1) (Go to 6d) ____ unpaid family (5) (Go to 6e)
 ____ paid family (2) (Go to 6f) ____ unpaid friends/others (6) (Go to 6e)
 - _____ paid friends/others (3) (Go to 6f) ____ unpaid professional (7) (Go to 6e)
 - ____ paid professional (4) (Go to 6f) ____ NA/Refused (9)
- 6d. 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.)

APPENDIX B

Consent Form

(patient)

MSU FAMILY CARE STUDY CONSENT FORM

The study in which we are asking you to participate is designed to learn more about the ways in which caring for an elderly family member affects the person providing the care.

Over the next 24 months, 1,235 caregivers will be interviewed five (5) times by a member nurse in the hospital from which you were discharged. Your participation is requested to have access to your medical record discharge summary and group health insurance numbers.

If you are willing to participate in this study please read and sign the following statement.

1. I have freely consented to take part in a study of family caregivers conducted by the College of Nursing and the Department of Family Practice, College of Human Medicine, at Michigan State University.

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- 2. The study has been described and explained to me and I understand what my participation will involve.
- 3. I understand my participation in this study is voluntary, will involve no cost to me, and that my decision will in no way affect my current or future health care.
- I understand that I may withdraw from participation at any time without penalty to me by calling 1-800-654-8219.
- 5. I understand that the results of this study will be treated in strict confidence and, should they be published, my name will remain anonymous. I understand that within these-restrictions, results can, upon request, be made available to me.
- 6. I understand that no immediate benefits will result from my taking part in this study, but am aware that my responses may add to the understanding of health care professionals and may influence future family care.
- 7. I understand that I have the right to seek further information about this study, and my rights relating to it, by calling the research office: (517) 353-0306 or toll free, 1-800-654-8219.
- 8. I understand that a member of the research staff may need to review part of my current medical record. I consent to allow access to the hospital discharge planning documents and understand that this information will remain strictly confidential.
- 9. I understand that a member of the research staff may wish to inquire about my group health insurance policy benefits to understand what benefits are available to me and compare these to what I am presently using. I give my consent for the hospital discharge coordinator to provide my group insurance(s) policy numbers with the understanding that they will remain strictly confidential

I, _____, state that I understand what is required of me as a participant and agree to take part in this study.

Patient Signature	Date
Guardian/Family Member	Witness.

APPENDIX C

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UCRIHS Approval

MICHIGAN STATE

UNIVERSITY

May 12, 1997

Barbara A. Given A230 Life Sciences TO

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

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 a ho

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 cartification. 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. RECENTLY

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.

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



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

OFFICE OF RESEARCH AND GRADUATE

STUDIES versity Committee of

isearch Involving Human Subjects Res (UCRINS) Michigan State University 6 Administration Building

East Lansing, Michigan 48824-1046

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

 $\mathcal{D}($ 1 David E. Wright Ph.D. UCRIHS Chair DEW: bed

cc: Charles Given

CHANGES :

Sincerely

e Michigan State University 16A is Institutional Diversity Excellence in Ad

ASU is an aller and appendix rated

MICHIGAN STATE

UNIVERSITY

October 24, 1997

TO . Barbara A. Given A230 Life Sciences

IRB#1. TITLS: REVISION REQUESTED: W/A CATEGORY: APPROVAL DATE: 97-680 PREDICTORS OF PHYSICAL FUNCTIONING IN ELDERLY TERMINALLY ILL CAMCER PATIENTS N/A 1-E APPROVAL DATE: 10/20/97 PR.

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

UCRIES 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 ranewal form (enclosed with the original approval latter 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 egain for complete review. PROFILE ...

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 advartisements that are applicable.



OFFICE OF RESEARCH AND

GRADUATE

48824-1046 \$17/355-2180 FAX: 517/432-1171

Re

PROBLEMS/ CEANGES : Should either of the following arise during the course of the work, investigators must notify UCRIRS 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.

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

STUDIES Sincerely. ersity Committee on ZE.L arch Involving Noman Subjects (UCRINE) David E. Wright, Ph.D. UCRIHS Chair Michigan State University 146 Administration Building DEWibed East Lancing, Michigan

The Michigan Shife University IOGA is institutional Diversity Excellence in Action

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